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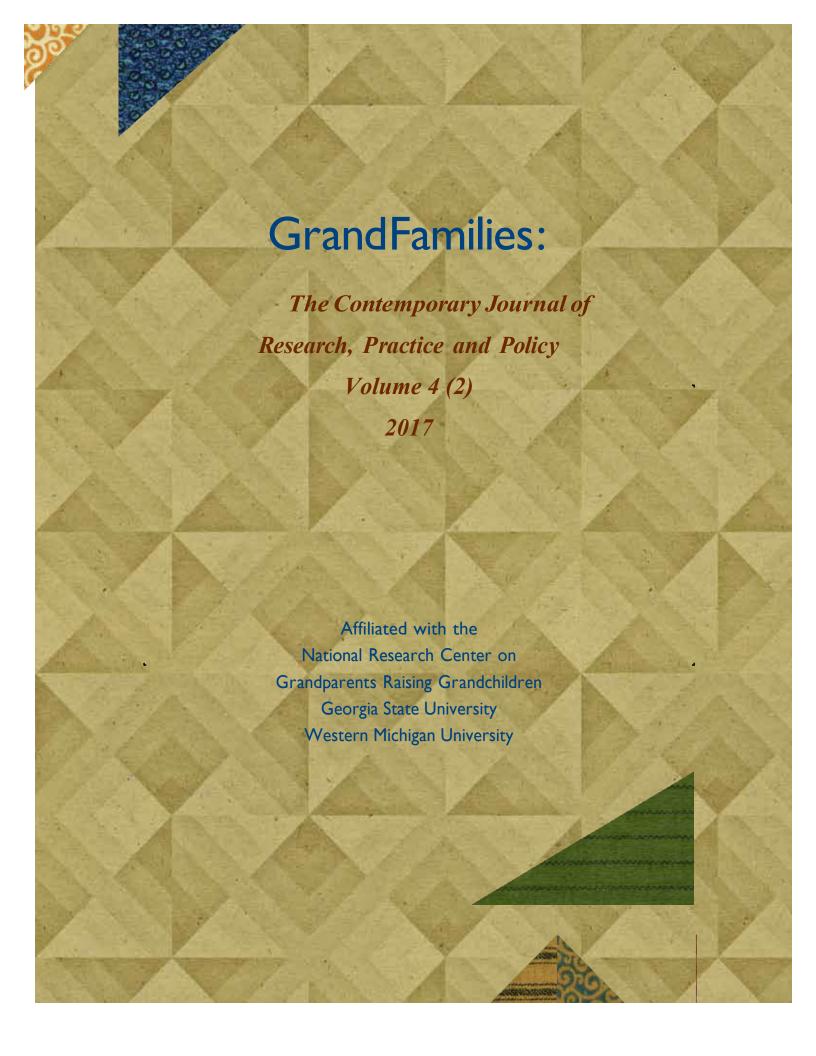
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Research Article

Mapping the Needs of Kinship Providers: A Mixed-Method Examination

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Abstract

This study utilized Concept Mapping (CM) to examine the needs of 105 kinship caregivers in one southeastern state, and to examine priority differences in conceptualization by placement type (formal vs. informal). CM is a mixed-method research methodology that employs multidimensional scaling and hierarchical cluster analyses to examine relationships among sets of data. Results indicate that kinship providers conceptualize needs via an eight-cluster solution, or *concept map*. As well, data suggest key priority differences between informal and formal caregivers in areas of financial, legal, and public outreach needs. After a brief review of literature about kinship care, this paper will explain results from the study, discuss findings in relation to previous works about kinship, and explicate practice, policy, education, and research implications derived from study findings.

Keywords: kinship, relative placements, grandparents, concept mapping

Child welfare systems are becoming increasingly reliant on relative family caregivers for the placement of maltreated children (Geen, 2004; Koh, 2010; Sampson & Hertlein, 2015). In 2014, there were an estimated 2.4 million youths being raised by relatives or close family friends in the United States (U.S.; Generations United, 2014). The U.S. Office of Personnel Management (n.d.) reported that over five percent of *all* children in America live in a kinship arrangement and the U.S. Department of Health and Human Services (2010) stated that approximately 25% of youth placed outside their

homes live with a relative. Indeed, as several authors (e.g., Wilson & Chipungu, 1996; Cuddeback, 2004; Denby, 2015) have aptly deduced, kinship care has become an essential component of the child welfare service array.

Despite this growing dependence on kinship care providers, research in the area of kinship care has not kept pace (e.g., Gleeson, O'Donnell, & Bonecutter, 1997; Ryan, Hong, Herz, & Hernandez, 2010). There are gaps and inconsistencies in the current literature (e.g., Cuddeback, 2004; Coakley, Cuddeback, Buehler, & Cox, 2007; Koh, 2010), and current literature offers few pragmatic steps for conceptualizing support programs for kinship caregivers (Denby, 2015). As a result, states have historically struggled to develop and implement programs aimed at supporting relative caregivers (Kolomer, 2000; Leos-Urbel, Bess, & Geen, 2002). Some (Gleeson et al., 2009; Strozier, 2012; Lin, 2014) have called for more research that explores the needs of kinship providers, particularly for those in informal custodial arrangements. This paper seeks to uniquely contribute to filling these gaps.

This study utilized a convenience sample of kinship providers in one southeastern state (N = 105) and employed a mixed-method research methodology known as Concept Mapping (CM). CM combines multi-dimensional scaling with hierarchical cluster analyses to compute visual depictions of data (Kane & Trochim, 2007). This research sought to explore how relative caregivers conceptualize needs related to kinship placements. Further, this study examined the prioritization of these needs by placement type (formal vs informal). After a terse review of the literature, we will explicate the CM processes utilized in this study, articulate the results, and discuss these results within the context of existing literature. We will conclude by identifying implications and apposite areas for future kinship research.

Background

Kinship Care Terminology

Understanding kinship care can be complex. In part, this complexity can be attributed to the divergent terminology and practices used to describe and implement these custodial arrangements (e.g., Ehrle & Geen, 2002; Bratteli, Bjelde, & Pigatti, 2008). Kinship care can be broadly defined "as the full-time protecting and nurturing of children by grandparents, aunts, uncles, godparents, older siblings, non-related extended family members, and anyone to whom children and parents ascribe a family relationship" (Child Welfare League of America, 2013, para. 1). Other terminology used to describe kinship care is "relative care" and "family and friends care", though these terms are most readily used in countries outside of the U.S. (e.g., O'Brien, 2012).

In essence, kinship care can be understood within the context of two overarching types of care: *formal care* and *informal care*. Formal care typically refers to a placement arrangement made by a child welfare agency with the authority to remove and place children, such as Child Protective Services (Strozier, 2012). These types of placements are tracked and data can be provided via state reporting systems (Bratteli, Bjelde, &

Pigatti, 2008). In a formal placement arrangement, the child welfare agency would typically remove the child from the care of the parents and place the child with a relative. Certain states permit placement with close family friends, sometimes referred to as fictive kin (U.S. Department of Health and Human Services [U.S. DHHS], 2010). Other states permit kin providers to become foster parents (also known as kinship foster care), thus *formalizing* the placement (O'Donnell, 1999; Kolomer, 2000). The process of licensing kinship providers as foster parents varies widely as there are few, if any, federal guidelines for these processes (Bratteli, Bjelde, & Pigatti, 2008).

Informal kinship care is defined as an arrangement "made by the parents and other family members without any involvement from either the child welfare system or the juvenile court system" (U.S. DHHS, 2010, p. 2). Different from formal arrangements, informal kinship placements are usually not coordinated by state child welfare systems, and as such, are not monitored (Gleeson et al., 2009). While these types of placements are often associated with a "family crisis" that leaves the birth-parent(s) unable to adequately care for the child (O'Brien, 2012, p. 128), in some instances these types of placements are necessitated by the physical or mental illness of the parent(s), military or civil service overseas, or other extenuating circumstances (e.g., U.S. DHHS, 2010). Informal kinship care may also be referred to as "voluntary kinship care" (e.g., Ehrle & Geen, 2002; Bundy-Fazioli & Law, 2005) or "private kinship care" (Gibson & Singh, 2010).

Need for Kinship Care

Over the last three decades, the need for kinship care has grown remarkably. In part, this growth was predicated on the burgeoning number of youth entering the foster care system (Leos-Urbel, Bess, & Geen, 2002). During the latter part of the 20th century, while the number of available foster homes was decreasing, the number of children entering foster care was on the rise (Wilson & Chipungu, 1996; Koh, 2010). Thus, many states shifted towards the use of kinship placements to assuage the burden placed on already strained child welfare systems (e.g., Bundy-Fazioli & Law, 2005; Koh, 2010).

Coinciding with these shifting foster care dynamics, federal policy began to address dynamics related to kinship care arrangements. For instance, Leos-Urbel, Bess, and Geen (2002) and Falconnier et al. (2010) explained that the Indian Child Welfare Act of 1978 served as an impetus for child welfare systems to focus on familial preservation and connectedness. Theoretically, these components of the policies are at the crux of the argument for focusing on kinship care placements (Berrick, 1997; Crumbley & Little, 1997; Bundy-Fazioli & Law, 2005). Further, the Adoption Assistance and Child Welfare Act of 1980 (P.L. 96-272) required states to seek the least restrictive, family-type home. Undoubtedly, placements with relative caregivers fit these criteria.

More recently, Congress acknowledged the importance that kinship arrangements play in caring for youth with the inception of the Temporary Assistance for Needy Families (TANF) in 1996. TANF policy explicitly declared that kinship families caring

for their relatives could seek monetary assistance to help with meeting the needs of the child. This benefit is commonly referred to as "child-only TANF" (e.g., Gibbs, Kasten, Bir, Duncan, & Hoover, 2006). Other federal policies such as the Adoption and Safe Families Act of 1997 (P.L. 105-89), particularly Section 303, and the Fostering Connections to Success and Increasing Adoptions Act of 2008 (P.L. 110-351), lend credence to the importance of kinship care in the arena of child welfare. Today, kinship care has become the preferred alternative to placing children who have been maltreated in foster care (Falconnier et al., 2010; Ryan, Hong, Herz, & Hernandez, 2010).

Research on Kinship Care. Research literature around the topic of kinship care is somewhat fragmented. While slightly dated, Cuddeback (2004) offered an excellent critical review of the literature that revealed a disjointed body of evidence pertaining to kinship care. This author described the literature as having "methodological limitations and significant gaps" that inhibit the understanding of kinship care (p. 623). Others have also discussed limitations in the kinship literature (e.g., Bundy-Fazioli & Law, 2005; Lin, 2014). These limitations in the literature can be attributed, at least in part, to divergent kinship terminology and practices (e.g., Ehrle & Geen, 2002; Bratteli, Bjelde, & Pigatti, 2008).

Limitations aside, several researchers have described the characteristics of kinship providers. In sum, researchers have found that kinship providers tend to be in poorer health, less educated, and have fewer financial resources than their non-kin counterparts (e.g., foster parents) (e.g., Berrick, 1997; Geen, 2004; Strozier & Krisman, 2007; Barth, Green, Webb, Wall, Gibbons, & Craig, 2008; Sakai, Lin, & Flores, 2011; Sampson & Hertlein, 2015). Additionally, research indicates that kinship care, particularly the informal type, appears to be most prevalent among peoples of color (e.g., African-Americans, etc.; Wilson & Chipungu, 1996; Bonecutter & Gleeson, 1997; Cuddeback, 2004; Harris, 2013).

Outcomes, particularly related to placement stability and permanency, associated with kinship care have also been examined. Exemplars include Perry, Daly, and Kotler (2012), who conducted a study among Canadian kinship providers, found that kinship placements were significantly more stable and were more likely to achieve reunification when compared to non-relative placements. Using a model that utilized propensity score matching across several states, Koh (2010) also concluded that youth in kinship arrangements were more likely to experience placement stability when compared to non-kinship placements. Koh and Testa (2008) found that permanency outcomes were attributed, in part, to differences between the two groups (kin versus non-kin), not necessarily the placement type itself.

While it is clear that kinship placements are preferred to non-relative placements, some researchers have pointed out negative outcomes associated with these types of placements. For instance, in reporting findings from a national survey of kinship care providers, Ehrle and Geen (2002) concluded that youth in kinship care "faced greater

hardships" and experienced food insecurity at a higher rate when compared to youth in foster care (p. 15). Farmer (2009), who conducted an examination of kinship care in England, found that children in kinship were more likely to live in "over-crowded conditions" (p. 331). In a longitudinal study with over 13,000 cases, Ryan, Hong, Herz, and Hernandez (2010) found that the risk for juvenile delinquency for adolescent males was significantly greater for individuals placed in a kinship arrangement when juxtaposed with those in a non-kinship arrangement. Indeed, some of these problematic outcomes may be associated with the lack of resources available to kinship care providers.

The implications of this literature review are clear: the use of kinship placements has grown over time, and given the current strain on the child welfare system, it is likely that the use of these types of placements will persist. As such, researchers should continue to explore the use of kinship placements. Specifically, these researchers ought to assess the needs of kinship care providers and delineate pragmatic ways that the child welfare systems can address these needs. Particular attention should focus on the needs of informal kinship caregivers (e.g., Kolomer, 2000; Cuddeback, 2004; Strozier & Krisman, 2007; Gleeson et al., 2009; Strozier, 2012; Lin, 2014). Researchers ought to assess these needs from the perspective of those perhaps most impacted: *kinship care providers* (e.g., Bundy-Fazioli & Law, 2005 Coakley, Cuddeback, Buehler, & Cox, 2007).

Current Study

We utilized Concept Mapping to explore the needs of kinship providers in one southeastern state. Our research sought to address current limitations in the literature by answering two (2) distinct, yet interconnected, queries: (1) How do kinship providers conceptualize their needs pertaining to having successful kinship placements; and, (2) Is there a difference in the way that informal kinship providers prioritize these needs when compared to formal kinship providers?

Study Context

With any research endeavor it is imperative to understand the context in which the study was conducted. This study occurred against the backdrop of several factors related to kinship care. For instance, kinship providers in this state were provided a monthly kinship care subsidy for relative children in their care. In 2013, there was a moratorium placed on offering these benefits to new kinship care providers, due to state budgetary constraints. Simultaneously, the state experienced significant increases in the numbers of youth in foster care, while national data indicated decreases in the number of youth in care (See Adoption and Foster Care Analysis and Reporting System [AFCARS] #22, 2014). Anecdotally, some practitioners and policy makers surmised that the loss of the kinship subsidy contributed to the rising number of youth in care (i.e., relatives were not able to take custody of their relative without the help of the subsidy).

Methods

Concept Mapping (CM) is a mixed-method, participatory research approach that analyzes qualitative data quantitatively (Kane & Trochim, 2007). CM had been used in a range of professions and disciplines (e.g., child welfare, physical health, mental health, etc.) and this method is particularly well-suited for conceptualizing and assessing needs among research participants (Miller, 2016). The application of this methodological approach for this study is unique. A literature review of academic and research databases revealed no published studies that use CM to explore and assess the needs of kinship care providers.

CM can be understood within the context of three overarching phases: (1) Generating Ideas/Statements, (2) Statement Structuring, and (3) Analyses. Because some readers may be unfamiliar with CM, the following paragraphs briefly outline the components the method entails. For a full explanation of the method, please see Kane and Trochim (2007).

Generating the Ideas

In CM, ideas are collected as qualitative statements. The statements are collected via brain-storming-type focus groups. Brainstorming is the activity generating ideas while in a group (Diehl & Stroebe, 1991). For this study, participants were invited to take part in one of seven brainstorming sessions held across one southeastern state. Brainstorming sessions included both formal and informal caregivers. Participants attended the groups geographically closest/most convenient for them and each brainstorming session lasted between 60-90 minutes. During these sessions, participants were asked to respond to the following prompt: "Generate statements that describe what kinship care providers need for successful relative placements." This prompt as well as the general and demographic information survey were piloted with a small group (n = 10) of kinship providers before being used for this study. We, the researchers, collated the statements from all of the brainstorming sessions and synthesized the statement set utilizing Kippendorf's (2004) approach to idea synthesis. This allowed for the elimination of redundant or unclear statements. The remaining statements comprised the *final* statement set, which included 68 unique ideas. The final statement set, delineated by cluster, and bridging values are included in Table 1. Please note that additional information related to the cluster and bridging values can be found in the Results section.

Table 1. Clusters - Statements¹, and Bridging Values²

Cluster: Financial		3. ongoing monthly stipends	0.30
1. monies for house modifications for	0.16	4. affordable child care	0.31
expanded families	0.10	5. start-up monies at the time youth	0.22
2. financial resources for	0.25	are placed with the relative	0.33
extracurricular activities	0.23	1	

6. access to one-time funds for		behalf of the child	
emergency situations that may arise	0.34	24. access to legal advice	0.42
7. clothing allowances for youth	0.43	25. legal standing in court	0.45
8. resources for youth to attend		26. affordable legal representation	0.62
college	0.92	27. consistent application of rules as	
9. medical coverage for youth in kinship care	1.00	they apply to kinship providers	0.64
Mean Bridging Value	0.45	28. police to help enforce custodial kinship arrangements	0.82
Cluster: Permanency		29. judges to recognize the importance	0.86
10. the kids not to be moved back and		of relative caregivers	0.00
forth between the parent	0.19	Mean Bridging Value	0.56
and relative		Cluster: Counseling	
11. do more to look for relatives before		g .	
kids are placed into foster	0.26	30. individual therapy for youth	0.43
care 12. case workers to continue to work on		31. therapist that have sliding-fee scale	0.48
reunification even if	0.27	32. consistent therapy providers so the	
placed with a relative	0.27	family is not being shuffled	0.48
13. not put caregiver "on the spot" about		around to different therapists	
making a placement	0.32	33. individual therapy for kinship caregiver	0.48
decision		34. family therapy	0.53
14. move to place in permanent custody		* **	0.33
of relative faster if	0.33	35. therapist that are familiar with dynamics (e.g., circumstances)	0.53
parent(s) is unable to take child back 15. structured visitation services to		of kinship care	0.55
facilitate visits between	0.34	36. individual therapy for birth parents	0.67
biological parents and youth	0.54		0.51
16. more involvement of paternal		Mean Bridging Value	0.51
relatives in kinship	0.36	Cluster: Family and Peer Support	
arrangements		37. ongoing peer-support groups	0.49
17. to make sure the placement is a good	0.50	38. peer-support groups that meet at	0.77
match for the youth	0.50	times that are "good" for	0.51
AND the caregiver 18. clear rules about the responsibility of		kinship providers	0.01
biological parents	0.53	39. virtual peer-support groups	0.55
19. freedom for kinship provider to act	0.50	40. kinship providers need mentors who	
like a parent	0.59	are familiar with the	0.58
20. therapist and counselors that follow	0.73	kinship system	
court orders		41. good relationships with family	0.62
Mean Bridging Value	0.40	members 42. support from extended family	0.02
Cluster: Legal		members	0.63
21. need to be heard in court	0.40	43. respite care	0.66
22. copies of all legal documents about		44. family members to understand the	
the child/youth	0.41	importance of kinship	0.69
23. ability to make legal decisions on	0.41	arrangements	

45. support groups for the youth in kinship care	0.71	importance of kinship providers	
Mean Bridging Value	0.61	Mean Bridging Value	0.46
Cluster: Training		Cluster: Resources	
46. training about social issues facing young people (e.g., teenagers)	0	63. accessible database of available resources for kinship providers	0.59
47. training on social media	0.01	64. better explorations (i.e., research)	0.66
48. training on gadgets such as cell phones, etc.	0.01	about what works and does not work in kinship arrangements 65. a warm-line to call and get advice	0.66
49. training offerings that are similar to that of foster parents	0.02	66. places that youth can stay for an	0.08
50. an online library of trainings that can be accessed anytime 51. training specific to reason child is in	0.04	extended period of time if the caregiver has extenuating health circumstances	0.75
kinship care (maltreatment type)	0.04	67. for kinship providers to be afforded the same benefits as	0.77
52. advocacy training to teach the caregiver hot to advocate for youth in various settings, such as school	0.09	foster parents 68. community events for kinship providers and youth (i.e., retreats, camps, etc.)	0.82
53. training about trauma and boundaries		Mean Bridging Value	0.71
for family kinship situations	0.10	Troum Dringing Value	0471
54. education about how to talk with child about kinship issues	0.13		
55. training for young people on how to live with older people	0.23		
56. education about what kinship care is for people outside the system	0.41		
57. training on legal processes and proceedings related to family care and rights	0.55		
Mean Bridging Value	0.14		
Cluster: Public Outreach			
58. do an awareness campaign about kinship care	0.43		
59. remove the stigma of kinship care	0.45		
60. need positive stories about kinship to be shared more (not just bad stories)	0.45		
61. need people to know that kinship providers are not doing it for the money	0.45		
62. everyone needs to recognize the	0.51		

Notes:

1. Clusters based on Multi-Dimensional Scaling and Hierarchical Cluster Analysis (HCA) of sorted data. Numbers ascribed to each statement are for reference only.

2. Clusters with lower values indicating more consensus of how ideas were sorted into those clusters by participants.

Sorting and Rating the Ideas

The process of sorting and rating the statements is known as statement structuring. Statement structuring refers to the sorting and rating of statements (Kane & Trochim, 2007). After the brainstorming phase was complete, participants were reconvened for a second meeting to structure the statements. Each participant took part in one brainstorming session and statement structuring session. Akin to the brainstorming sessions, we held seven structuring meetings and the brainstorming sessions lasted between 60 - 90 minutes. During these statement-structuring meetings, each participant was given a set of 3x5 index cards. These cards contained statements from the statement set (one statement per card). Each participant received a set of 68 cards, meaning that they all received the entire final statement set. Statement sorting exercises were done individually.

Then, participants were asked to sort each of the statements into piles and provide a name or "label" for each pile. Theoretically, the sorting exercise is designed to examine a *meaning* relationship among statements in the set. Presumably, participants sorted the statements into piles based on a perceived conceptual relationship.

Once the statements were sorted, participants were asked to rate each of the statements in the set on one variable: importance. Specifically, participants were asked to rate how important each statement is to successful relative placements. Importance was measured via a Likert-type scale ranging from one to five. For the scale, 1 indicated *not important at all*, and 5 indicated *very important*. The sorting and rating of the statements were done in one session that occurred between 8 – 10 weeks after the initial brainstorming sessions. Conceptually, the rating exercise is designed to examine a *significance* relationship among statements in the set. Note: These research procedures were approved by a university Institutional Review Board (IRB).

Analysis

CM entails the use of advanced multivariate analyses, namely multidimensional scaling (MDS) and hierarchical cluster analysis (HCA). At the outset of the analyses, a sort matrix is computed for each participant. This binary matrix details how each participant sorts each idea in the statement set with other ideas in the statement set. Then, these individual matrices are collated into an aggregate matrix for all participants. Numbers in the aggregate matrix range from zero (meaning no participants sorted the statements together into the same pile), up to the number of total sorters (Mpofu, Lawrence, Ngoma, Siziya, & Malungo, 2008). High matrix values denote some

consensus about the conceptual relationship between particular statements; low values indicate little consensus (Brown & Bednar, 2004).

Once generated, the aggregate matrix is analyzed via MDS, which is a series of mathematical and statistical computations that delimit data structures in space (Kruskal & Wish, 1978). For CM, MDS employs a two-dimensional solution, which produces coordinates, along an x and y continuum, for each of the statements in the final statement set. After the MDS analysis, HCA is performed. Romesburg (2004) explained that this procedure analyzes similarities in data structures and employs a clustering process. For this study, coordinates derived from the MDS procedure were used as data input for the HCA analysis. In turn, using Ward's (1963) algorithm, cluster parameters for the data are defined.

Results

Participants

A total of 105 participants took part in this study. Participants were recruited via a self-selected, purposive sampling procedure. A flier regarding the study was sent out to entities/agencies involved with formal and informal kinship care providers. Participants were asked to contact the researchers if they were interested in participating in the study. Then, participants were contacted to attend the sessions previously discussed and participate in the study. Participant demographic information is included in Table 2.

Table 2. Description of Participants (N = 105)

Characteristic	Informal Kinship Providers N (Valid Percent)	Formal Kinship Providers N (Valid Percent)	
	n = 63(60%)	n = 42(40%)	
Gender			
Male	13(20.6)	7(16.7)	
Female	50(79.4)	35(83.3)	
Race			
African American/Black	5(7.9)	1(3.4)	
Caucasian/White	56(88.9)	25(86.2)	
American Indian	1(1.6)	3(10.3)	
Asian	1(1.6)	0(0)	
Missing	0	13	
Education Level			
No degree	9(14.3)	3(10.3)	
High School diploma/GED	38(60.3)	17(58.6)	
Associate's degree	7(11.1)	3(10.3)	
Bachelor's degree	7(11.1)	5(17.2)	
Master's degree	2(3.2)	1(3.4)	
Missing	0	13	
Employment Status ¹	<u> </u>		
Employed	11(18)	4(13.8)	
Unemployed	50(82)	38(86.2)	
Missing	2	0	

Relationship to Child(ren)		
Grandparent	58(91.9)	40(95.2)
Great-grandparent	2(3.2)	1(2.4)
Great-great-grandparent	1(1.6)	1(2.4)
Other ²	2(3.3)	0(0)
Mean Age in years (SD)	63.6(8.1)	62.17(8.9)
Mean Number of children placed via kinship (SD)	1.46(.78)	1.89(1.2)
Mean age of children placed via kinship (SD)	10.5(3.9)	9.7(3.3)

¹ Employed outside the home either fulltime or part-time

Independent samples t-tests revealed no significant differences between informal and formal caregivers in terms of age (t = .69, p > 0.05), number of kids being care for (t = -1.6, p > 0.05), or age of children being care for (t = .76, p > 0.05), respectively.

Concept Map

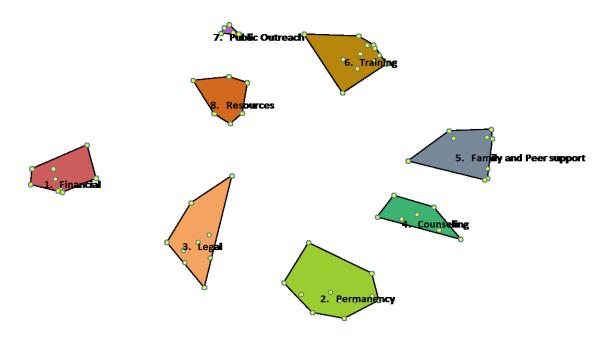
The MDS analysis of the overall similarity matrix emerged after 17 iterations; the final stress value for this analysis was 0.26, which falls into the acceptable range (e.g., Kane & Trochim, 2007; Rosas & Kane, 2012). The stress value indicates that there is a "good fit" between the aggregate similarity matrix and the point cluster map.

The final point cluster map contained eight (8) distinct clusters, as illustrated in Figure 1. Clusters included: *Financial, Permanency, Legal, Counseling, Family and Peer Support, Training, Public Outreach*, and *Resources*. Cluster names were identified based on the labels ascribed to each pile in the sorting exercises previously discussed. These names capture the overall theme, or concept, of the statements contained in each cluster. As earlier indicated, the point cluster map is a product of the using the output from the MDS analysis as input for the HCA analyses. Each point on the point cluster map represents one of the 68 unique statements derived from the final statement set.

^{2.} Both individuals reported being an Aunt to the child(ren) in their care

Figure 1.

Point Cluster Map

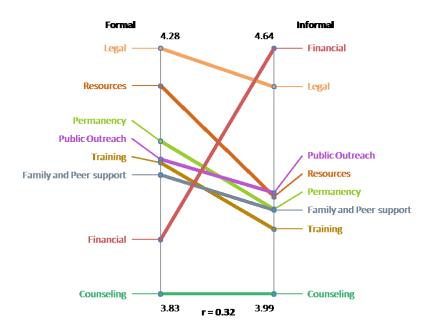


Clusters, including statements, and bridging values are outlined in Table 1. Bridging values range from 0 to 1, and indicates how often a statement is sorted in a cluster grouping. Lower bridging values indicate more cohesion, or consensus, about how participants sorted statements to a cluster, when compared to other clusters (e.g., Donnelly, Huff, Lindsey, McMahon, & Schumacher, 2005). As Table 1 indicates, mean bridging values for the final cluster point map ranged from .14 to .71.

Importance Ratings

As previously mentioned, participants sorted each of the statements on the variable *importance*. To examine priority differences in the conceptualization between formal and informal kinship care providers, we initiated a Pattern Match. This visual depiction of rating data allowed for comparison of both groups on one variable (e.g., importance). Figure 2 illustrates a Pattern Match comparing Formal and Informal kinship providers on the Importance variable. Please note that this Figure is best utilized for examining the rank order of the clusters between these two groups. For actual importance ratings for each group, please refer to Table 2.

Figure 2. Pattern Match – Importance



The correlation coefficient between ratings for these two groups was 0.32. To further explore differences in importance ratings between the two groups of caregivers, we commenced a Welsh's t-test, by cluster. Table 2 comprises a summary of these results.

As Table 2 indicates, the analysis detected significant differences in mean importance ratings between formal and informal providers for the *Financial*, *Legal*, and *Public Outreach* clusters. In all of these instances, Informal providers rated statements in these clusters significantly higher than did Formal caregivers.

Discussion

The purpose of this study was to conceptualize the needs of kinship care providers. Additionally, this study sought to examine differences in priority areas, specifically related to importance, of this conceptualization between formal and informal providers. The following section discusses relevant points related to the overarching research questions posited earlier in this narrative. For clarity, this section is delineated in a way conducive to explicitly answering those questions.

Research Question #1: How do kinship providers conceptualize their needs pertaining to having successful kinship placements?

Participants in this study conceptualized needs in eight distinct areas: *Financial*, *Permanency*, *Legal*, *Counseling*, *Family and Peer Support*, *Training*, *Public Outreach*, and *Resources*. Bridging values suggest that there was the most consensus about ideas belonging in the *Training* cluster, which has a bridging value of .14. Conversely, statements in the *Resources* cluster were the least cohesive, with a bridging value of .71.

In terms of the statements and clusters comprised in the *point cluster map* (See Figure 1), several components of the data are congruent with existing literature. For instance, statements contained in the *Family and Peer Support* cluster include: 37. ongoing peer-support groups; 39. virtual peer-support groups; and, 42. support from extended family members, among others. Many of these ideas have been captured in the current literature. A host of researchers (e.g., Strozier, 2012; Hawkins & Bland, 2002, etc.) have discussed the benefits of peer support groups for kinship providers. Additionally, research by Stozier, Elrod, Beiler, Smith, and Carter (2004) suggested that incorporating virtual aspects of training can be effective in supplementing these social supports. All of these points are evident in these participant data.

Other researchers (e.g., Green & Goodman, 2010) have touted the importance of wider family participation in kinship placements. Data from this study suggest that familial support and understanding are a specific need of kinship providers, as evidenced by the *Family and Peer Support* cluster. Indeed, family involvement can be an important component of successful kinship placements. Sampson and Hertlein (2015) found that kinship providers have reported strained relationships with family members due to taking on the role of raising a relative. Conceptualizing successful placements based on this family involvement may speak to a similar dynamic among these participants, and the need or desire to address that dynamic.

Several pieces of data in this study also indicate that kinship providers need to be more involved with aspects of decision-making related to the youth in their care. Statements in the *Legal, Permanency*, and *Family and Peer Support* clusters explicitly identify being more involved in the decisions making process related to kinship placements. Addressing this aspect as a need is congruent with previous assertions made by a number of authors (e.g., Gleeson, O'Donnell, & Faith, 1997; Ryan, Hong, Herz, & Hernandez, 2010).

Data from this study also sheds light on new areas of need that have not been widely explored. For instance, though the legal needs of kinship providers have been identified (e.g., Strozier, 2012), this area has seldom been explored in the literature. Statements in the *Legal* cluster include: 21. need to be heard in court; 22. copies of all legal documents about the child/youth; and access to affordable legal representation, among others. Though addressing the legal needs of kinship providers can be complex, these data indicate that focusing on this area may be necessary for successful kinship placements.

Permanency is another interesting concept, particularly as it applies to kinship care. According to the U.S. DHHS (2010), once a child is removed from their home, permanency is "returning them home as soon as is safely possible or placing them with

another legally permanent family" (para. 1). Some research suggests that permanency efforts can stall once a child is placed with a relative caregiver (Gaska & Crewe, 2007). These data, particularly statements included in the *Permanency* cluster, suggest that kinship providers need child welfare workers to make a more concerted effort to move towards permanency in a timelier manner.

Data related to the *Public Outreach* cluster is another that has seldom been addressed in the current research literature. Statements in this cluster suggest that kinship providers may believe that kinship arrangements, or the motives behind these arrangements, are misunderstood. Though the importance of public messaging and outreach has been explored in child welfare in general, and in foster care, specifically (Leber & LeCroy, 2012), this notion has not been examined in kinship care. Data from this study suggest that kinship providers believe that there needs to be a broader, more general understanding of kinship care.

Research Question #2: Is there a difference in the way that informal kinship providers prioritize these needs when compared to formal kinship providers?

In terms of the overall importance ratings, informal kinship providers tended to rank statements in all clusters as more important than did formal kinship providers. Based on these data, there is some difference in the "importance" priority areas of the conceptualization between informal and formal kinship providers. See Figure 2 and Table 2. The highest-rated cluster for formal caregivers, *Legal*, had a mean rating of 4.28 (on the five-point scale). The highest-rated cluster for informal caregivers, *Financial*, had a mean rating of 4.64. In terms of rank-order for importance, both groups rated the *Counseling* cluster as the lowest. Informal caregivers did rank statements in this cluster as more important than did formal caregivers, with mean ratings of 3.99 and 3.83, respectively.

As Table 2 illustrates, there were some statistically significant differences in importance ratings for three of the clusters in the *point cluster map*. Informal kinship providers rated the *Financial, Legal, and Public Outreach* clusters as significantly more important than did formal caregivers. From a practical standpoint, statistical differences in the ratings between these two groups make sense. For instance, data from this study suggest a glaring priority difference associated with financial needs. One previous study by Strozier and Krisman (2007) found that formal caregivers tended to have higher household incomes than informal caregivers. What's more, formal participants in this study may have been receiving a state kinship care subsidy, which the informal caregivers were not eligible to receive. These points suggest that informal caregivers may have more of a financial need than do formal caregivers, and this differential need manifested in the ranking data for this study.

Differences in the *Legal* cluster may also be attributed to the process of placing youth in kinship care. As indicated in the literature, formal kinship placements are most often handled by a governmental child welfare agency, which entail judicial involvement. As a point of context, all youth before the court in the state in which this study occurred

are appointed an attorney to represent their interests throughout the court proceedings. Further, relatives who are looking to be granted custody of youth will appear before court. Thus, parties involved in formal kinship arrangements may have more access to legal advice and be more involved in legal processes, than informal caregivers.

Anecdotal evidence suggest that informal providers are often frustrated in the day-to-day care of youth, particularly as it relates to legal consent. During the brainstorming sessions of this study, participants reported having problems "signing the kids up for school" and "getting them to be seen at the doctor's office" without the appropriate legal custodial documents. In many informal kinship arrangements, the biological parent(s) maintain(s) legal custody of the child, while the kinship provider carries out the day-to-day care activities. The differential ratings for statements in this cluster may be attributed to a greater need for legal resources among informal caregivers.

One important caveat related to the participant rating data is that participants were instructed to rate each statement vis-à-vis each other statement. That said, it is imperative to understand that just because a particular cluster is "low" in terms of rank order, does not mean that it is unimportant. For instance, the lowest rated cluster for both groups was the *Counseling* cluster. That does not mean that counseling services are not important; however, it does indicate that participants viewed other statements in the set as more pertinent.

Limitations

As with any study, this one is certainly not without limitations. For instance, all participants in this study were kinship providers in one southeastern state. The sample consisted of mostly grandparent, female, and Caucasian participants. Including additional participants may have yielded different data structures (e.g., Point Concept Map) and priority ratings. As well, additional demographic information, such as income, may have provided additional contextual information that would offer a deeper understanding of the results.

Because CM couples a qualitative and quantitative analyses, limitations associated with reliability and validity are present. In terms of CM methodology, Trochim (1989) explained that "validity is meant to refer to the degree to which a map accurately reflects reality" (p. 106). Though the researchers did take steps to clarify statements as they were provided during the brainstorming sessions and provide clear instructions associated with statement structuring exercises, future studies should look to validate (or not) findings associated with this study. To meet this end, Dumont (1989) suggested examining the trustworthiness of "conceptual representations" (p. 81) by comparing maps structured by hand, with those constructed via statistical computations.

Reliability refers to the ability to replicate aspects of a study and ensuring reliability using CM can be challenging given the iterative, multistep process associated with CM. To address limitations associated with reliability, future researchers may have participants sort statements on two different occasions and compare the sort data (e.g., Jackson & Trochim, 2002). Additionally, individual sort matrices could be compared

with those of the participant sample (e.g., Trochim, 1993). Undoubtedly, future research should take these limitations into account and should look to address these concepts as they pertain to CM methodology and its use with kinship participants.

Implications

This study offers a number of implications for kinship programming, education and training, and research. The following paragraphs briefly outline salient implications that can be derived from this study.

Practice and Policy Implications

Practice implications in several areas abound. For instance, though kinship placements may be preferred to non-relative foster placements (Ryan, Hong, Herz, & Hernandez, 2010), it is imperative that these types of placements are critically assessed to ensure that the relative can adequately meet the needs of the child. Likewise, it is necessary that this assessment include the impact that any placement will have on the caregiver. Research suggest that most relative caregivers are grandparents (e.g., Generations United, 2014), as is the case with this study. As these caregivers age, indubitably, caring for young children will place a burden on these caregivers. As data in the *Permanency* cluster indicates, practitioners must ensure that that any relative placement is a good "match" for the youth *and* the caregiver.

Another important point is that kinship services, as with any child welfare service, cannot be left solely to governmental agencies. Data in the *Resources, Public Outreach, Training, Family and Peer Support*, and *Legal* clusters suggest that the community become more involved in providing supports to kinship providers. As such, practitioners should engage communities to foster and develop a system of care that recognizes the important role of kinship providers. In turn, this engagement may encourage other service providers and social service entities to deliver services and supports aimed at nurturing successful kinship placements, thus assuaging some of the needs identified by participants in this study. The final point cluster map for this study can serve as the framework for this engagement.

There are a number of policy implications that stem from this study. Perhaps most importantly, states may want to adopt policies that afford kinship caregivers, particularly those in informal arrangements, financial resources to adequately provide for their relative. Even though kinship providers may be eligible for child-only TANF benefits, few care providers actually receive the benefit (e.g., Nelson, Gibson, & Bauer, 2010). Further, based on these research data, specifically the *Finance* cluster, resources beyond the TANF benefit may be warranted. This point is certainly consistent with other evidence that has suggested the most pressing need of kinship providers is financial (e.g., Geen, 2003; Sampson & Hertlein, 2015).

While some states allow for kinship foster care, this is not the case for all states. As such, states that do not offer this option may consider allowing kinship providers to become foster parents, thus making them eligible to receive foster care rates and per

diems. Adopting such a policy may also warrant changing existing foster parent approval processes to be more conducive to kinship placements. Approving kinship providers as foster parents, thus formalizing the kinship care arrangements, may afford the kinship provider more resources related to the needs (e.g. clusters) identified in the *point cluster map*.

Indeed, the stark reality is that by formalizing a placement, relatives may have more access to needed resources. However, relatives may have trepidation about formalizing these placements for fear of retribution from the biological parents. As well, while some have pointed out that relative placements have cultural significance, particularly for Black or African-Americans and other peoples of color (Wilson & Chipungu, 1996; Harris, 2013), these individuals may be hesitant to become involved in formal governmental processes due to perceptions of historic systemic racial biases. Hence, practitioners and policy makers should be cognizant of how these practices and policies may play out differently across population groups.

Training and Education Implications

Kinship caregivers receive far less training compared to non-kinship (e.g., foster parents) caregivers (Cuddeback, 2004). In fact, some caregivers, specifically those in informal arrangements, receive no training at all. Even in instances where training is available to kinship caregivers, many of these providers are unaware of the opportunities (Kolomer, 2000). These factors in mind, it is important that public and private entities conceptualize, implement, and evaluate training and educational opportunities for kinship providers, both formal and informal, alike.

These data, specifically statements in the *Training* cluster, offer some pragmatic areas in which these trainings can be developed. For instance, several statements lend credence to the notion that kinship providers need training specific to caretaking for young children and adolescents. These data are congruent with a generation gap (e.g., Cuddeback, 2004). Trainings around social media and issues, trauma and maltreatment, and how to engage their relative in discussing issues related to kinship can be invaluable to kinship providers.

A point of interest in the *Training* cluster is statement 55. *training for young people on how to live with older people*. This data suggest that kinship providers recognize that kinship arrangements can be a big adjustment for the youth, and that these providers are particularly concerned about the "age gap" between the kinship provider and the relative youth. Currently, kinship services (support groups, trainings, etc.) overwhelmingly focus on caregivers. Services and programs targeted at meeting the needs of kinship youth should be considered in future programmatic development.

This study also suggest that service providers need to be better educated about kinship care. Without question, kinship arrangements can be uniquely complex (Stozier, Elrod, Beiler, Smith, & Carter, 2004; Denby, 2015). Therefore, education and training specific to kinship arrangements are also pertinent to providers that may be tasked with working with kinship caregivers. Ideas in the *Resources, Counseling, Legal*, and *Public*

Outreach clusters indicate that kinship caregivers believe that providers of all sorts (e.g., social workers, mental health professionals, those working in the legal system, etc.) need to be more familiar with kinship dynamics. Curricular adaptions, course electives in post-secondary majors (social work, counseling, law, etc.), and continuing education offerings may be a way to provide the knowledge needed to more adeptly engage and proffer services to kinship providers and their families.

Research Implications

This study offers palpable research implications. Perhaps, central to these implications is the idea that the needs of informal and formal kinship providers differ. While researchers have asserted that the needs of these providers are similar (e.g., Strozier & Krisman, 2007), data from this study suggest that there are key differences in priority areas between the two groups. Researchers should continue to explore the complex and evolving needs of kinship providers, with particular attention to any differences by caregiver type. Variables such as placement type (e.g., informal vs. formal), race, and relationship type (aunt/uncle, grandparent, etc.) ought to be considered.

Within the kinship research landscape, evaluation tools related to assessing kinship placements are needed (Cuddeback, 2004; Falconnier et al., 2010). CM methodology has proven useful for the development of such tools in previous research (e.g., Miller et al., 2013), and data from this study may serve as the foundation for the development of such tools. Rosas and Camphausen (2007) have documented this process. Additionally, assessing the ability and knowledge of providers (e.g., clinicians, attorneys, etc.) and general perceptions of kinship care may also be apposite areas for future research.

Finally, an area of kinship research that needs attention is exploration of the youth perspective in kinship arrangements. Though very few studies have examined the youth experience as it relates to kinship placements, there are some studies that may serve as the foundation for these efforts (Pilkauskas & Dunifon, 2016). Prospects for this type of research include dyad interviews with caregivers and youth, conceptualizing supportive programming, and/or replicating this study with youth in kinship arrangements, to name a few.

Conclusion

This paper uniquely applied a mixed-method research approach to conceptualize the needs of kinship providers and examine priority differences of these needs, by participant group. Results indicate that the needs of these caregivers are multifaceted, and may differ by placement type. As the use of kinship providers continues to grow, it is imperative that researchers continue to examine these needs. This paper explicates several pragmatic implications for more adeptly working with kinship providers and serves as a framework for future research.

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Research Article

Social Support and Survival Strategies of Older African American Grandmother Caregivers

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Abstract

The effects of caring for grandchildren on grandparents' emotional and physical well-being have become a significant area of focus in behavioral and medical research. Research suggests that African American grandmothers may experience increased mental and physical health challenges due to their caregiving stressors. To buffer the adverse influence of stress, caregivers often rely on informal social support from family and/or community members. In this study we explored older, African American caregivers' management of their emotional well-being within the context and conditions of available to minimal social support from family and community. During an 18-month period, seven caregiving grandmothers participated in three face-to-face, audiotaped, semi-structured interviews; eco-map and genogram data were included to understand the contextual complexities of caregivers' social support and their strategies for survival. Using constant comparative analysis, six interrelated themes revealed grandmothers operated along a continuum of reliable to unreliable social support. In the context of these varying ranges of social support, four sub-themes depicting their survival strategies were identified: being strong, self-sacrificing, receiving help and selfcompassion. Utilization of each survival strategy was dependent on grandmothers' perception of where they fell on the continuum of reliable to unreliable social support. Grandmothers who engaged in being strong and self-sacrificing engaged in stress-related health behaviors, such as emotional eating, smoking nicotine, disruptive sleep patterns and postponement of self-care. We offer specific practice recommendations for addressing the emotional and physical health needs of grandmother caregivers.

Keywords: grandmother caregivers, depression, social support, stress, women's health

Introduction

In 2012, 2.7 million grandparent caregivers in the United States and about 1 in 3 are grandparent-maintained households with no parent present, often called "skipped-generation" households" (Ellis & Simmons, 2014). In skipped generation households, across racial and ethnic groups, African Americans were 13% likelier to live in a "skip" generation household compared to 7% of Whites, 4% of Latinos, and 1% of Asians (Livingston, 2013). It is more likely for an African American child to live in a household with a grandmother and a single parent or a grandmother and no parent compared to their racial counterparts (Ellis & Simmons, 2014). Minkler & Fuller-Thomson (2005) highlighted that African American grandparent caregivers in skipped-generation households were younger, female, less educated and had limited economic resources compared to their caregiving peers. Confirmed by Ellis & Simmons, children in these households are most likely to be in poverty. Caregivers take on this responsibility in response to crises such as substance abuse, incarceration, HIV/AIDS or community violence resulting in death of a parent (Crewe, 2012; Conway, Jones, & Speakes-Lewis, 2011; Joslin, 2002; Stinson, 2010; Young and Smith, 2000). Previous studies have revealed being an African American grandmother, low-income, middle aged, single, with lower levels of education and receiving inconsistent social support are more likely to experience mental health stress and depression than their counterparts (Carr, Hayslip, & Gray, 2012; Kelley, Whitley, & Campos, 2013; Musil, Warner, Zauzniewski, Wykle, & Standing, 2009; Smith & Hancock, 2010; Whitley & Fuller-Thomson, 2017; Whitley, Lamis, & Kelley, 2016).

Skipped-generation households may be either formal (public) or informal (private). Formal arrangements are commonly referred to as kinship care, the full-time nurturance and protection of a child by extended family members or including non-related persons who have a kinship bond with the child (Harden, Clark, & Maquire, 1997). Informal arrangements occur outside of the child welfare system and are an agreed upon relationship between parent(s) and the grandmother. There have only been a few studies exclusively focused on private, the most common type of kinship care arrangement (Bunch, Eastman, & Griffin, 2007; Simpson, 2008; Simpson & Cornelius, 2007; Simpson and Lawrence-Webb, 2009). African American grandmother caregivers with no parents present are the most vulnerable group of grandparent caregivers and there remains minimal research about how they are coping with the stressors associated with caregiving. We focus on skipped generation households of African American grandmother caregivers who are in private kinship care arrangements, caring outside of the formal kinship care system, as they may not have access to equitable services and funding. Their individual and collectively identities - race, class, gender and age - stigmatized and disadvantage them in countless ways. They are the most marginalized group of caregivers and likely the most distress due to their complex intersection of identities and caregiving demand. Against this background, it is important to recognize the interplay of multiple forms of oppression on African American grandmother caregivers may be mitigated by the support they receive from their family and community. Thus, in this qualitative study we explore how older African American grandmother headed households respond when faced with consistent and inconsistent social support from family and community. We use multiple lenses, ecological perspective (Bronfenbrenner, 1979) and the womanist perspective (Collins, 2000), to highlight how caregivers engage in survival strategies and how it affects their emotional and physical well-being.

Literature Review

The cost of depression is a disabling chronic health condition placing a burden on families, communities and health care systems (Greenberg, Fournier, Sisitsky, Pike, & Kessler, 2010; Richardson et al., 2012). Although, African American women are less likely to have higher depressive symptoms compared to Whites; they are more likely to have higher depressive symptoms compared to African American men. African Americans are less likely to undergo treatment and the chronicity and severity of depression is greater within the African American population (Simpson, Krishnan, Kunik, & Ruiz, 2007). The mental health needs of older African American women are of public concern and addressing their mental health needs is paramount. Informal grandparent caregivers, particularly African American grandmothers, have experienced mental and physical health cost due to their care demands (Baker & Silverstein, 2008; Musil & Ahmad, 2002).

Studies have revealed that African American grandmother caregivers have experienced increased stress and numerous health challenges directly related to their caregiving roles (Carr, Hayslip, & Gray, 2012; Clotty, Scott, & Alfonso, 2015; Carthron, Bailey, Anderson, 2014). Longitudinal studies that utilized nationally representative data for examination of depressive symptoms among grandparent caregivers found grandparents residing in multigenerational homes, both caregiving or co-residing, had elevated risk of depression (Minkler, Fuller-Thomson, Miller, & Driver, 1997; Kelley, Whitley, Campos, 2013; Whitley & Fuller-Thomson, 2017). For example, Kelley, Whitley, & Campos (2013) found that nearly 40% of the 480 African American grandmother caregivers in their study scored in the clinical range on psychological distress, which raised considerable concern regarding the well-being of African American caregiving grandmothers. Whitley & Fuller-Thomson in their 2017 study of skipped generation households revealed a quarter (25%) was diagnosed with clinical depression at some point in time.

Our interest in African American grandmother caregivers' physical health status stems from a common concern that they are at a higher risk of chronic illness, disability and functional impairment due to their caregiving demands (Schulz & Beach, 1999). Women caregivers experience chronic stress as a result of their role leading to adverse health outcomes (Pearlin, Mullan, Semple & Skaff, 1990). Caregivers are at greater risk for morbidity and mortality compared to non-caregivers (Lee, Colditz, Berkman, Kawachi, 2003; Schulz & Beach, 1999; Christakis & Allison, 2006). Caregiving research has yielded mixed results because the relationships are complex and may be attributed to caregivers' prior history of poor health (Baker & Silverstein, 2008; Conway, Jones, Speakes-Lewis, 2011), lack of time devoted to self-care (Carthron, et al., 2015.; Carr, Hayslip, & Gray, 2012; Minkler & Fuller-Thomson, 1999) as well as an increase in depression and anxiety that arises from parenting children experiencing past emotional trauma, various health issues, learning disabilities and challenges related to anger management (Doley, Watt, & Simpson, 2015; Kelley, Whitley, & Campos, 2013; Kelley, Yorke, Whitley, & Sipe, 2001; Whitley, Fuller-Thomson & Brennenstuhl, 2015). To buffer the adverse influence of stress, caregivers often rely on social support from family and/or community members.

Perceptions of Social Support and Well-Being

A line of research has revealed social support is a major protective factor against psychological distress (Hayslip & Kamaniski, 2005; Hughes, Waite, LaPierre, & Lou, 2007).

Dressler (1991) posited social support is based on a person's perception of help or assistance from other individuals during difficult times. The type of social support received may be instrumental aid from members, such as child care, emotional support, financial assistance, physical care, transportation, decision making and providing for necessities such as food, clothing, and shelter (Billingsley, 1992; Hill, 2003; Martin & Martin, 1978, McAdoo, 1982; Stack, 1974; Taylor, 1985). Research examining the link between social supports and wellbeing among grandparent caregivers revealed an association between social support and depression (Musil, Gordon, Warren, Zausznieswski, Standing, Wykle, 2011; Warren-Findlow, Laditka, Laditka & Thompson, 2011). Severely fragile grandmother maintained households with strained family resources had the worst physical health, greater depressive symptoms and problems in family functioning (Musil, et al, 2011). Grandmother caregivers who received emotional support from family members and friends reported better emotional health (Warren-Findlow, Laditka, Laditka & Thompson, 2011). They also reported that familial support as well as support from friends buffered the effect of daily discrimination. Grandmother caregivers who perceived lower social support and poor physical health were linked to greater levels of depression (Musil & Ahmad, 2002; Musil, et al, 2011; Carr, Hayslip & Gray, 2012). Musil & Ahmad (2002) found that instrumental support was not associated with decrease levels of depression; however, perception of support was linked to lower levels of depression.

There is a clear indication that social support may serve to prevent and treat the adverse influence of stress on physical and mental health (Dressler, 1991; Pearlin, Mullan, Semple & Skaff, 1990; Carr, Hayslip & Gray, 2012; Kelley, Whitley, & Campos, 2013; Warren-Findlow, Laditka, Laditka & Thompson). In the grandparenting literature, family resources have been conceptualized as "those instrumental resources that are essential for raising children and include income, food, shelter, and access to health care" (Kelley, Whitley, Sipe, & Yorker, 2000, p. 313). Kelley, Whitley, Sipe and Yorker (2000) investigated the predictors of psychological distress across social supports, subjective family resources and physical health among 102 African American grandmother caregivers. They found that grandmothers who reported fewer family resources and poorer physical health tended to score higher on the psychological distress measure. In their follow-up study (Kelley et al., 2013), similar results indicated elevated psychological distress was explained by poor physical health of grandparents and perceived inconsistency of family resources. In a one-year longitudinal study, researchers found that grandparent caregivers reported better health with greater informal social support, over time (Hayslip, Blumenthal, Garner, 2015).

Several studies found that grandparent caregivers are overwhelmed with their caregiving responsibilities and may not be receiving support from extended family members (Burton, 1992; Carr, Hayslip & Gray, 2012; Jendrek, 1994; Musil, et al, 2011; Smith, 1994; Stokes and Greenstone, 1981). In Burton's (1992) study, African American grandmother caregivers reported not receiving support from their relatives. Similar to Stokes and Greenstone (1981) and Smith (1994) studies, primarily African American grandmothers, found that caregivers did not perceive their support from kin and extended kin as consistent and reliable. Social support is an important resource to leverage for grandmothers meeting the demand of caregiving. African American grandmothers caring outside of the child welfare system often draw upon informal social support, family or community members, to mobilize resources (Clotty, 2012). They often perceive formal social services as unreliable and unavailable to meet their caregiving needs (Carr, Hayslip & Gray, 2012; Simpson & Lawrence-Webb, 2007).

There are findings about the consistent support they receive from family and community (Burton and Jarrett, 2000; Simpson, Smith & Davis, 2016) but minimal about the absence of some caregivers' ability to solicit support from family members on a regular basis. The relationship among caregiving demands, social supports and well-being are further complicated by existing health disparities, such as race, class, gender, age, and other sociodemographic attributes (Hughes, Waite, LaPierre, & Luo, 2007). Older African American grandmother caregivers are in a uniquely vulnerable position because as older adults age, sources of emotional and instrumental support often decrease. Particularly for caregivers who family members have been hampered by structural inequalities such as poverty, substance abuse, disease, and community violence (Simpson, 2009).

Survival Strategies of African American Women

Based on Lazarus & Folkman's (1984) cognitive theory of psychological stress and coping, coping strategies have been categorized into two domains, problem-focused (direct action taken to resolve the source of stress) and emotion-focused (engaging in behavior to reduce emotional distress caused by the stressful situation). According to Lazarus & Folkman's (1984), the use of both problem-focused and emotion-focused forms of coping reduces stress. A majority of the grandparenting literature have used elements of this theory to examine the coping strategies of caregivers. A study reported that caregivers who utilized less active coping and more avoidant coping methods experience depressive symptoms (Musil & Ahmad, 2002); while caregivers who utilized problem-focused and emotion focused forms of coping, such as counseling and after-school programs, had reduced stress (Ross and Aday, 2006). These forms of coping serve as protective factors against stressors perceived by grandmother caregivers. The most common coping strategies employed by African American caregivers are cognitive coping and affective coping; behavioral and active coping (Picot, 1995). Unfortunately, African American grandmother caregivers who experience higher levels of acute and chronic stress have developed adaptive and maladaptive coping mechanisms (Kane, 2007) but tend to use spirituality as a primary coping strategy (Navaie-Waliser et al., 2001). This finding confirms studies that found caregivers tend to rely on prayer and biblical scriptures (Dilworth-Anderson, Boswell, & Cohen, 2007; Minkler & Roe, 1993; Poe, 1992).

The race and gender of African American grandmother caregivers creates a unique stress experience resulting in different coping strategies (Black, Murry, Cutrona, & Chen, 2009; Woods-Giscombé, 2010; Woods-Giscombé & Lobel, 2008). A cultural adaptive response to pain and suffering is the expression of strength (Beauboeuf-Lafontant, 2007, 2009), furthered conceptualized as Strong Black Woman/Superwoman Role of Strength (SWS); Woods-Giscombé, 2010). Accordingly, Woods-Giscombé and Black (2010) finds that SWS manifested as a superwoman role with attributes of: "(a) an obligation to manifest an image of strength; (b) an obligation to suppress emotions; (c) resistance to being vulnerable or dependent; (d) determination to succeed, even in the face of limited resources; and (e) an obligation to help others" (p. 3). These coping mechanism are survival strategies learned by their fore mothers through their lived experiences. African American women have historically "included an accumulation of racial inequality; social, political, and economic exclusion; and medical under service. These inequities decrease access to resources and heighten susceptibility to psychological stress and premature stress-related illness" (Woods-Giscombe, 2010, p. 669). Women who embrace the superwoman role encounter negative consequences,

such as delayed self-care, emotional eating, inadequate sleep, anxiety, depression, and impaired physical health (Woods-Giscombé, 2010).

African American women exercise a survival process that they have grown accustomed to by making sacrifices to promote the collective well-being of their self, family and community (Giddings, 1984). These adaptations may come at a high cost to their own emotional and physical well-being. We need further exploration to how caregivers manage their own mental and physical well-being within the context and conditions of informal social support that may not always be available. We pay attention to how grandmothers manage when faced with weakened informal social support from family and community. We explore heterogeneity on these dimensions and the need to understand grandmothers' survival strategies and how it affects their well-being.

Theoretical Frameworks

The ecological perspective (Bronfenbrenner, 1979) and the womanist perspective (Collins, 2000) provided multiple lenses to explore how caregivers managed within the context and conditions of available to minimal informal social support. Through these lenses we increased our understanding of how participants' gender, race, class, age, and access to resources shape their experiences and perceptions of reality. The ecological perspective recognizes the relationships between and among the four levels within a social system: microsystem, mesosystem, exosystem and macrosystem. In this study, the micro system included family relationship patterns among any members residing inside the home (i.e., grandmother, grandchildren, and any adult children). The meso system included interrelationships between any person(s) or setting(s) affecting grandmother caregivers (i.e., relationships among caregivers, their adult children, and family members; caregivers and social service programs or other communities' entities). The exo-system level included social factors such as neighborhood conditions that affect the micro-system and mesosystem elements (i.e., gangs, drugs, or violence). The macro-system level included broad ideologies within society that influence grandmother caregivers (i.e., culture, politics, economics, religion, etc.).

To address how gender, class, race, and power intersect to shape inequities, a womanist perspective (Collins, 2000) was utilized to examine grandmother caregiving within a broad sociohistorical-political context of gender, race, age, income, and class. Grandmother caregivers' values and life experiences were at the center of analysis and their voices define their own life experiences as they see themselves rather than how others see them (Collins). In this case, the perspective frames questions for understanding how African American grandmother caregivers define their own realities and survival strategies. Womanism fits well with the purpose of this study because it provided a framework for understanding how African American grandmother caregivers define their own realities and coping abilities. Grandmothers were viewed from a culturally relevant perspective, through which to examine, interpret, and understand the enduring resilience of adaptive strategies. Womanism perspective provided the researcher with the ability not only to assess the strengths of grandmother caregivers but also to be conscious of the challenges faced by their role as caregivers. As proposed by Dickerson (1995) and supported by other female scholars (Banks-Wallace, 2000; Barbee, 1994; Bryson and Lawrence-Webb, 2001; hooks, 1989), the best approach to understanding the lives of African American women is to seek information and explore all dimensions of a African American woman's standpoint with and for African American women. Both the ecological and womanist perspectives support qualitative investigation. The assumptions within these

perspectives require exploration of the issues directly from the lived experiences of participants which cannot be obtained through standardized measures or secondary databases; they rather require entry into the world of grandmother caregivers and their environment.

Methods

Sample. The sampling technique for the study was purposive sampling of grandparent caregivers, which came from the closed client roster of the University of Maryland School of Social Work's Family Connections program, a community based prevention and intervention program targeted toward families "at risk" of child neglect. The sample of participants selected for the study was based on the following criteria: 1) race--African American; 2) gender—female; 3) household arrangement--grandmother - maintained household with no parent present or one parent present and 4) legal arrangement –voluntary caregivers, not involved in kinship foster care. The final seven grandmothers who completed the study were no longer involved in Family Connections. All of the names used in this report are pseudonyms

A fairly homogeneous sample (n=7), respondents ranged in age from 52 to 74 years. Four grandparents were either widowed or divorced and the remaining were never married (n=3). With regard to formal education, most (n=5) had not completed high school education. Two women, however, did report having "some college," both had an associate's degree or professional trade certification. Majority (n=6) were not working at the time of the interview. One participant retired from her job due to her disability, three had resigned as a result of their full-time caregiving role, and the remaining two did not have an extensive history of paid employment. As unpaid laborers they primarily worked in rearing their siblings, children and grandchildren most of their lives.

Caregivers' status was informal, meaning grandmothers were not involved in kinship care services at the time of the interview. The number of grandchildren cared for by these participants ranged from 1 to 7. Five caregivers were caring for at least one child with behavioral/emotional problems. Six caregivers were caring for their grandchildren due to drug-related deaths, drug abuse and/or incarceration of parents. Only one caregiver, Mrs. Truth, had two parents living in her home. This great-grandmother was interviewed because she had four remaining great-grandchildren whose parents were not present in her home.

Depression Scale and Caregiver Well-being Scale. Two measures of well-being were used in this study: depressive symptoms and caregiver well-being (Table 1). Depressive symptoms was assessed by the 20-item, Center for Epidemiological Studies Depression (CES-D) survey (Radloff, 1977) with an emphasis on affect. Responses were coded on a scale ranging from 0 (symptom experienced less than 1 day in past week) to 3 (symptom experienced 5-7 days in past week), and totaled with higher scores indicating more depressed mood. Thus, the range of scores is 0-60. The traditional cut point is a score of 16 or higher used to identify those at risk for developing clinical depression. Three of the seven grandmothers, Ms. Coppin, Ms. Ferebee and Ms. Moses, had scores higher than 16 and all three were receiving mental health treatment. In the grounded theory section, a discussion about these grandmothers' use of social supports and their coping strategies will be examined.

The Shortened Version of the Caregiver Well-Being scale, developed by Tebb (1995), rated the extent to which caregiver activities have been met in a timely manner. This scale consists of two sub scales: caregiver activities (e.g. buying food, home repairs, rewarding self and financial future); and caregiver needs (e.g. eating a well-balanced diet, getting enough

sleep, expressing love and anger). Each sub scale consists of eight items scored 1 (rarely) to 5 (usually) and was totaled and averaged which allowed the researcher to compare one participant to another. Thus, the range of averaged scores is 0-5. See Table 1 for individual scores.

Data Collection and Design. Data collection took place over an 18-month period, between the years 2000 and 2001, which included three face-to-face, audiotaped, semi-structured interviews. Data collection consisted of the primary author, a 34-year old, African American, female, who conducted each interview which lasted between 1.5 hours to 2 hours, and was conducted in the grandmother's home. Additional support with the design and implementation was provided by a 46-year-old African American male with numerous years of training and teaching qualitative research methodology.

The study protocol consisted of an observation of the participant in their environment and three face-to-face, audiotaped, semi-structured interviews. The interviewed addressed many facets including demographics data to perceived social supports from extended family members and community; family and community stressors, survival strategies and mental well-being. Genograms and ecomaps were utilized to capture caregivers' variations in their informal and formal social support structures. The purpose of these tools was to have a diagrammatic view of the presence or absence of family and non-family resources within the informal and formal social support structures of the grandmothers. Initial genogram and ecomap data were verified during the second and third interviews. Interviews lasted between one hour and thirty minutes and two hours. During each interview, observations were noted and following each interview, field notes were reviewed for accuracy. Documentation included verbal and nonverbal cues of the participant and the researcher-participant interaction, as well as the setting of the participants' home.

Data Analysis. Data analysis occurred concurrently with data collection and was analyzed using constant comparative method (Strauss & Corbin, 1998). Through the process of "open coding" a core variable which occurs frequently in the data, linked various data together and explain much of the variation in the data (Strauss & Corbin, 1998). Following identification of core variables, these concepts are grouped into categories and then compared with each other to ensure that they were mutually exclusive and covered behavioral variations (Strauss & Corbin, 1998). Once categories were defined, the researcher identified the specific properties and dimensions of each category and identified subcategories. The formulation of properties and dimensions assisted with the formulation of patterns along with their variations (Strauss and Corbin, 1998). In this stage, data was compared with other data in a category to evaluate whether that data belonged in that particular category or another, which is known as axial coding (Strauss and Corbin, 1998). Axial coding involved the examination of structure, the contextual events related to why a phenomenon occurred and the process, which is how one acts when an event occurs related to a phenomenon over a period of time. Because of the data analysis technique, the researcher was able to understand how grandmothers managed within a context of minimal social support and how these strategies affect caregivers' well-being.

Rigor. Prolonged engagement and persistent observations, peer debriefing, member checking and triangulation were five methods used to ensure findings were credible. Prolonged engagement and persistent observation was ensured by the length of time spent in

the field in order to learn the culture of participants. The peer debriefing group consisted of two African American females and one African American male, who had years of experience managing qualitative data analysis and who were engaged in their own research with African American women using qualitative methods. Face-to-face meetings on a bi-weekly basis were conducted to discuss the development of codes, categories and themes. They provided feedback as well as challenged the working themes derived from the data. Additional steps were taken to engage in member checking which involved having grandmothers review the themes and interpretation, and conclusions to ensure findings reflected their lived experiences.

Peer support group members provided feedback, challenged working hypotheses and ensured that the researchers' findings accurately reflected the experience of grandmother participants. Member checking involved reviewing with each grandmother participant the accuracy of data collected which was conducted during the second interview and the third interview when grandmothers had an opportunity to alter or change their input regarding the data collected for genograms and ecomaps. Also, grandmothers were presented with major themes developed from their interviews to ensure research findings reflected their caregiving experiences. Furthermore, the use of interviews, observation notes, memos, code notes and theoretical notes were documentation utilized to ensure dependability and confirmability. These documents were the groundwork for an audit trail, which is important for it linked the findings back to the data collected. Based on the activities discussed above it can be said that this researcher did a reasonable job of ensuring methods of credibility were adhered to throughout the study.

Ecological Context of Grandmother Caregivers

This section presents the community context in which grandmothers were raising their grandchildren. Grandmothers resided in the west side of Baltimore City, known for its challenges in addressing community violence, drugs, and pockets of poverty (Simon & Burns, 1997). Baltimore city has a population of roughly 614,664 people, African American children represent the largest ethnic group in the city, representing 68%; Whites represent 17%; Asians represent 2 % and Hispanics represent 6 % (U.S. Census Bureau, Kids Count Data Center, Baltimore City, Maryland, 2016). In Baltimore City, 24% of families were living below the poverty level and of those families, 15,637 or 28% have children younger than age 18 (U.S. Census Bureau, Quick Facts, Baltimore City, Maryland, 2016). Similar to impoverished urban cities, Baltimore City had been hit hard by the crack-cocaine epidemic. The high rates of drug activity, crime, unemployment, and juvenile delinquency have affected the structure and functioning of family and community resources. In the state of Maryland, 141,040 grandparents are co-residing with their grandchildren and of those 30 % are skipped generation households, no parent present, 39% are aged 60 years and over and 14% are living in poverty (Ellis & Simmons, 2014). The legal arrangements of these grandparent-maintained households are unknown; however, it can be estimated that large proportions of grandparents are providing informal care (Mayfield, Pennucci, & Lyon, 2002).

Results

Through analysis of transcripts, six interrelated themes contributed to understanding the context of how African American grandmother caregivers coped within the context and environments of informal social support. Grandmother caregivers operated along a continuum of *reliable* to *unreliable* informal social support. Unreliable support described family members

as being overburdened with their own responsibilities. Grandmothers felt they did not have the emotional, financial or social resources to assist with caregiving as result of their own challenges with poverty, health, or other life challenges. At the other end of this continuum, reliable support, grandmothers described family members grandmothers depended on to assist with grocery shopping, medical appointments, finances, and occasional respite care. In the context of these varying degrees of reliable and unreliable social support, four survival strategies emerged: being strong, self-sacrificing, receiving help and self-compassion. Grandmothers' survival strategy employed was dependent on the continuum of reliable to unreliable informal social support. Below we describe the two opposite ends of the continuum of unreliable to reliable support. Within each context the narratives presented describe how caregivers operated on a continuum from being strong to self-compassion as they had greater access to resources. We conclude with how their survival strategies affected their emotional and physical well-being.

Unreliable Social Support

Unreliable social support was depicted as family members who were not able to participate in exchange of family resources due to being absent or deceased as a result of drugs, community violence or poor health (e.g., HIV/AIDS, cancer, or heart disease). As depicted by Ms. Coppin, a 68-year-old, retired, divorced grandmother caring for three grandchildren; four of her five adult children, with the exception of her son, were affected by drug abuse and incarceration

[Daughter's name] was a long-distance operator, telephone operator. Blew it for drugs. [second daughter] is an artist and she could, she laid the tile in my house when I needed it, and could do all kinds of work ... [third daughter] is a tailor and interior decorator...and Yvonne [fourth daughter] is a licensed plumber, and they [daughters] want drugs. And they come to me on the third [pay day] looking for loans, for money. Steal. I've lost microwaves; the children lost games, TV's because of them.

Ms. Coppin's depiction above describes how her entire family was adversely influenced by the crack cocaine epidemic thus destroying the helping traditions of her family. These exo-system forces undermined the familial social support structures necessary for the healthy maintenance of family systems. Caregivers' descriptions represent the aftermath of distressed families suffering from the crack-cocaine era (Dunlop, Golub & Johnson, 2006). As a result, these family members were not able to assist due to drug dependency, community violence, or medical conditions. Her support primarily came from one male family member (adult son) residing outside the grandmother's home, who helped in all areas except shopping, cooking and cleaning. Female support came from Mrs. Coppin's siblings in the area of emotional support. Remaining females (four daughters) were affected by drug abuse and incarceration but these daughters would provide support only in times of crisis. There were no adult family members residing inside the home to provide daily support in the area of household chores (e.g. cooking and cleaning).

Even when family members co-resided in the home, caregivers still faced difficulty with seeking contributions toward caregiving as they were overburdened with their own hardships. Grandmothers described family members as being too busy coping with their own stressors to contribute toward caregiving on a consistent basis. For example, Mrs. Truth, a 74-

year-old great-grandmother caring for her seven great-grandchildren; Mrs. Truth had four adult children. She lost her only two sons to drug overdose between the years of 1995-1996. These two sons left a generation of grandchildren and great-grandchildren that was cared for by Mrs. Truth. The biological mothers of these grandchildren were not providing support due to drug addiction, incarceration and death. Mrs. Truth's two daughters also left a legacy of grandchildren and great-grandchildren. Biological mothers of these children were also not able to provide support as two mothers were killed and the remaining was addicted to drugs or neglected their children. Similar to Ms. Coppin, as well as remaining grandmothers in this study, families were distressed by the devastation of crack cocaine era which occurred most often in inner cities in the 1980s and 1990s, resulting in sub-cultural behaviors, such as child abuse and neglect and family dissolution (Dunlop, Golub & Johnson, 2006).

The availability of supportive resources in Mrs. Truth's informal social support network was limited by the impact of drugs, alcohol and mental health. Both granddaughters resided in Mrs. Truth's home and had young children that were primarily cared for by Mrs. Truth. One granddaughter was described as being unable to provide consistent support for she suffered from a mental disorder and was addicted to alcohol. In the excerpt below, Mrs. Truth presented difficulties she had with getting support from this granddaughter,

She don't take her medication [for manic depression]. She drinks (alcohol) every night on that step. Every night she's drinking. And then in the morning, she don't want the children to say nothing to her...she does nothing but stay up in that room all day...And she's just miserable. She wakes up miserable...she's not stable, she's an unstable young lady....She done cut her wrist four times behind a sorry low-lifed. And she had these children. She don't want them...And the only way I keep her in my house is so I can watch them [great-grandchildren], cause she will hurt them...She is what you call a manic depressive.

The other granddaughter was described as "trying to get on her feet". This daughter was recently released from incarceration, and sought treatment for her drug addictions. Mrs. Truth related,

She was out there, but she straightened herself up. And she's ready to take [her] grandson and I am ready to give him to here....She's been clean now for six years and she's working. So I think she can have her son back...Her apartment should be coming through by the end of this month and than she will be taking [him].

Mass incarceration is no longer affecting just Black men. Women of color are the hardest hit. As noted by Lee & Wildeman (2011), Black women's social networks are riddled with imprisoned family members and neighbors compared to White women, men and even Black men. Mass incarceration of Black women have resulted in added harm to grandmother headed households who are left to care for children often in state-sanctioned poverty due to the unresponsiveness of human service agencies (Simpson & Lawrence-Webb, 2009).

Remaining family members residing outside of Mrs. Truth's home were her sister, two daughters and the biological mothers of her great-grandchildren. These family members were

largely burdened by their own responsibilities or dealing with drug abuse:

So even when she [biological mother of three grandchildren] come to get the children, now during the summer, I would ask her to keep them, but she is a rock head, she's a crack head, she's in and out of jail...Well, yes she (grandmothers' biological sister), she's not what you call flat down in the bed. She gets up, she goes to the store and everything, she cooks dinner for just her and her husband, she has a granddaughter and she's in school now. So, I wouldn't put, I wouldn't really disrupt her (grandmother's biological sister) to say, 'Well, you keep all of this,' because I got one, I wouldn't put that on my worse enemy. So, and then the rest of them is not gonna volunteer. To keep them, nobody really wants to keep him [grandson with emotional and behavioral problems]....

Although Mrs. Truth's sister was not able to provide support in the areas of household, respite, appointments and at times of crisis, she could count on her sister to provide informational and emotional support. She related discussing concerns with her sister on a daily basis. Mrs. Truth reported her sister was her primary source of emotional support. However, she related not having anyone else to talk to,

...there are times that I would like to have someone to talk to. I don't have no one because everybody in the neighborhood, outside the neighborhood, bring all their problems here....

Grandmother caregivers having limited emotional support from family members were consistent among grandmother caregivers in family networks with a limited pool of supportive resources. The types of support Mrs. Truth reported not receiving any help were in the areas of respite care and crisis. The lack of support for respite and crisis in family social support networks with unreliable support was a common theme. She shared the following,

...Last year I had pneumonia, I had the walking pneumonia, I went to the doctor's and he wanted to hospitalize me and I said how can I with all those kids and no one to take care of them. (the doctor said) So what'd you do if you dropped dead or go into the hospital? I told my doctor I'll cross that bridge when I come to it; I wasn't dead yet.

Survival Strategies: Being Strong or Self-sacrificing

In this context of unreliable support, caregivers managed by *being strong* or *self-sacrificing*. These were survival strategies caregivers employed when they were minimal to no supportive resources in maintaining their caregiving role. In the present study, being strong was a culturally appropriate and expected survival strategy when faced with adversity. As previously discussed, all grandmothers were coping with the effects of drugs, poverty and oppression in their families and communities.

Being strong: Attributes of being strong were keeping emotions hidden, not allowing one to release negative emotions for fear of breaking under pressure, relying only on their

internal resources to manage their caregiving role. Being strong meant that they maintained a false sense of self-composure by not revealing their true feelings. This sense of self-composure was important for it allowed them not to emotionally break down under adversity. For example, Mrs. Truth had two sons who died from drug addiction between the years of 1995-1996 and were caring for their offspring. She stated,

...And sometimes, honey, it's not easy. It's so hard to, I just don't cry anymore; I cried out. And crying don't help. And I'm at the point now that if I start crying, I will never stop. I won't know how to stop because I've held it back so long and I went through so much with my second husband and his family. And then I lost my two sons back to back; and there wasn't no one that I could lean on. So there had to be nobody but God that brought me through all of this...a couple of times this year...I feel like I wanted to cry, just wanted to holler and scream. But I knew I couldn't do that because if I did that, they wouldn't of have no one because I'd would of been gone. And I just can't give in to those kinds of things because it bothers me and it hurts. I've never cried behind either one of my sons because that's their life.

Embedded in Mrs. Truth's statement was that she had to be emotionally strong in order to continue her role as a caregiver. She was left with the responsibility of caring for her grandchildren and to allow feelings associated with sadness and grief would interfere with her role of caregiving. In her statement, "...it bothers me and it hurts" revealed that she was feeling pain associated with these losses and her added responsibility of caring for others. However, dwelling on these feelings would only weaken her resolve and her ability to care for others. Carthron, Bailey and Anderson (2015) found similar findings in their study as African-American grandmothers engaged in self-silencing believing there was no other choice but to quietly carry their adversities without breaking down physically or mentally.

Self-sacrificing: Attributes of self-sacrificing captured caregivers' survival strategies who did not have the time *nor* took the time for self. They often did not enjoy a personal life outside of caregiving. Self-sacrificing captured the lived experiences of African American caregivers who had to rely on their own internal resources to meet their personal needs and grandchildren's needs. This was a necessary survival skill for grandmother caregivers who had fewer resources in their informal and/or formal social support. Women acted in this capacity because they needed help from family but oftentimes this help was not forthcoming. For example, Ms. Ruffin aged 53 and caring for four grandchildren, described how family members are coping daily with poverty, health, and responsibilities of their own,

My oldest sister, she's got, what is it, cerebral palsy... she can't get around too good . . . And my next oldest sister, she's a foster mother, so she got about four foster kids of her own, and a little grand boy. And my next sister, she's a heart patient, so she's not capable of taking care of them or helping me. . . My next sister . . . she works and she has three kids of her own, so she's not capable of really helping me. All of them have their own responsibility. And if they could help, like I say, they may call on the phone, do a little talking.

When grandmothers were asked about why they engaged in self-sacrificing behavior, they consistently responded that asking for help was not the problem but rather who was available to provide help. As stated by Ms. Chinn, a 65 year-old, caring for two grandchildren, "I ask for help and don't get it a lot [of] times. Ask for help and don't get it!" Ms. Coppin, 68 caring for three grandchildren related,

Well, some people have help in their households from their grandmothers or aunts, uncles who raise them. But they also have a younger, a sister-in-law or might [have a] daughter or somebody in the household. I don't have anybody in my household to do anything...

Grandmothers often felt internal and external pressure to operate independently in a context of limited or inconsistent support from various social structures. Grandmothers sacrificed their own lives to meet their family members' expectations to care, and social service agencies who often threatened that their grandchildren would be removed if they did not assumed full parental authority. Ms. Moses, aged 52, shared her experience about how she sacrificed her career goals to fulfill family expectations,

... training for Return to Independence [fictional name of program for job training]. And every day they kept calling me, my sisters and they, "you need to take your grandchildren. My sisters kept calling me on the job, getting on my nerves, saying I need to take the grandchildren. Because they had no one else to take them. The mother, she wasn't taking care of them properly. She [biological mother] could no longer... and she got so she couldn't even take care of him. You would go around where she [biological mother] was living at, she'd be sitting up there shaking up drug needles in a box, sitting there in the door all highed-up, he (grandson) wandering the street and he wasn't no more than about a year old, all around [name of] Street, could of got killed, eating out the garbage can. Well she fixed food and stuff, but she wasn't stable at that time of taking care of him. So they [sisters] kept calling me about him [grandson]. So it took me maybe about a month and I decided I would go and get 'em all. So I stopped the training and I took all four....

Self-sacrificing, placing her own personal goals on hold in order to meet the needs of her grandchildren were necessary for the well-being of her grandchildren. Ms. Moses reported that after assuming care for her grandchildren, she had very little time for herself and her own personal needs. She reported:

"...but a lot of times I let myself go lacking so that I can take care of them [grandchildren], what their needs are. And after their needs are all taken care of, and then I reach back or relax and work on mines."

Sacrificing their own needs to meet the needs of their grandchildren was a necessary adaptive strategy to meet their caregiving demands. Grandmother caregivers felt they were not offered any other alternative from family members and/or community providers regarding the care of their grandchildren. This required that they remain strong and/or self-sacrifice their

own needs to meet societal expectations of their caregiving role.

Reliable Social Support

On the opposite end of the continuum, grandmothers described a few of their family members as reliable. These family members assisted with grocery shopping, medical appointments, finances, and occasional respite care. Although both men and women fell into this category, grandmothers perceived their sons as more reliable as they had the economic and material resources to regularly assist grandmothers (Simpson & Cornelius, 2007). The following themes are grandmothers' perspective of their family supportive resources. Ms. Chinn, 65 year old, caring for two grandchildren, described how her son, uncle of the grandchildren, who assisted her on a daily basis by providing male mentorship to her grandchildren, she reported, "My son is basically my backbone. He's my back-up person." This quote captures the perceptions of grandmother caregivers' reliance upon their sons or other family members to assist in their caregiving role. Ms. Moses', aged 52, caregiver of 4 grandchildren had a significant male friend who was available to provide additional support in the areas of material means, emotional support during times of crisis. She also had an adult son (uncle of grandchildren) who resided in her home who assisted with her grandchildren. In the excerpt below, Mrs. Jones, who cares for one granddaughter, adult daughter with Downs Syndrome and mother, with Alzheimer's describes how her son, who once had an alcohol addiction and does not live in the home, was currently a source of support and could be relied upon to meet her caregiving, needs,

...my son used to be an alcoholic. Now he says he's, what you, he call himself, an inactive alcoholic. He hasn't drunk in about 4-5 years. Now, I can call on him, like I need something from the store...

She furthered described her son's role:

"Like, now I have a meat man who brings all my meats but like my vegetables. He picks up all the vegetables ...buys all the vegetables like, beans, cabbage, corn, our canned goods, potatoes, onions. He buys all of that...And he takes her (dependent grandchild) when she needs new shoes; she goes to [name of store] in Maryland Parkway. And he sees that she gets to the store to get her shoes. And what else? And he'll come down if I need anything. Yeah, he'll fix the doors for me if they need to be fixed. But most of my children are very helpful"

As depicted below, remaining family members in her informal social support network were available to assist her with grocery shopping, meeting medical appointments, finances and sometimes respite care. Mrs. Jones described how female and male family members played primary roles in caring for her grandchild and herself:

"[Name of person], that's my son's daughter, she's the one that will come and see that [name of person] (dependent grandchild) has a dental appointment, a eye appointment, any kind of appointment she has to go to; she does....And my oldest daughter....she sees that I get to all my doctors' appointments. She's a

correctional officer over at [name of job site]; and she works the night shifts. And she works the night shift just so she can ensure that I get all my appointments... And she buys all of the like soap powder, soap, bleach, washing liquid, paper towels, toilet tissue. She does that. She gets it at Sam's Club because she's a member....The godmother [of her dependent grandchild] goes to the school when they have functions because her godmother is now retired from Social Security. She was one of the biggies up there. And she goes up and the teacher knows she can always call me or call the godmother and we can get it together...".

Survival Strategies: Receiving Help and Self-compassion

In the context of reliable support, caregivers managed by receiving help from their family social support. Grandmother caregivers with available supportive resources in a desired area were able to engage in asking and receiving help. As summarized by Ms. Chinn, in order to move beyond self-sacrificing, help had to be available. Their ability to operate from this framework was possible only when they received the needed resources desired from informal and formal social support structures. Grandmother caregivers who received support from informal and formal structures primarily operated from this framework.

Receiving Help. The key to receiving help was based on caregivers' willingness to seek help from family members *and* family members' having available resources to meet their needs. Ms. Chinn, cared for one child with behavioral/emotional problems, had no family members residing inside her home. Support came from paternal grandmothers in the areas of emotional, respite and informational. Support from other family members (siblings and biological mother of grandchild) were minimal due to drug addiction, medical conditions and poverty. She described how her son provided support when she was faced with the reality of giving up her grandchildren after being denied community services for clothing and food:

"When I moved over East Baltimore ... I done moved all over town with these children trying to hold on to em, but I can't get no help! You know! (Long pause) And my son, he came up and I started telling him about they didn't have no clothes and I was giving them up (respondent is tearful). That was a time too. He cried and I cried.... So he said, "Come on, let's go get them clothes." ... Took me and bought their clothes, you know. Thank God I don't have to go through it no more (tears in her eyes, voice choking up)..."

Prior to her son's involvement, Ms. Chinn shared how she requested help from various agencies and help was not forthcoming. In her above excerpt, she stated "...I done went to my limit..." meaning she relied upon and used all of her internal resources to feed, clothed and provide shelter for her grandchildren. Although she asked for help from community providers, it was not provided and she turned to her family for assistance. Ms. Chinn's ability to maintain her role as a caregiver was possible by the help she received and continued to receive from her son. If help was not forthcoming from either family or community, she would have been left with no other alternative but to release her grandchildren to state custody. Asking and not receiving help can push caregivers to manage by being strong or engaging in self-sacrificing behavior

Given the limited availability of support in grandparenting households, three grandmothers sought help from mental health agencies to assist with managing their care demand. Ms. Coppin, Ms. Ferebee and Ms. Moses, had scores higher than 16 on the CES-D depressive scale (Table 1) and all three received mental health treatment. Ms. Moses clinical score was 23, Ms. Ferebee, 41 and Ms. Coppin was 43. Their entry into therapy was precipitated by a crisis event related to their grandchildren. All felt being in therapy provided them with a safe forum to discuss their emotions related to their caregiving role. Ms. Coppin's therapist was once her grandson's therapist and she viewed her therapist as her primary source of social support. Ms. Ferebee received various services from community agencies due to her granddaughter's disability. As with Ms. Coppin, her mental health services were initiated during a crisis episode with her grandchild. This finding of African American grandmother caregivers receiving services from mental health agencies is new to the grandparent literature. For the three grandmothers receiving mental health services, they no longer felt they had to be strong in all areas to cope and they were provided a safe forum to discuss their concerns.

Self-compassion. Self-compassion related to grandmother caregivers creating a space in which they could enjoy themselves without feelings of guilt. It meant taking time and having the time to enjoy their personal activities. To achieve this need, grandmother caregivers required support for child sitting services from informal and/or formal social support structures. The need for self-compassion was often expressed by caregivers but not fulfilled by many. Expressed by Mrs. Jones "...if I can get an hour just for me to do nothing...then I can sit here and watch a program without having to do something for somebody..." and confirmed by Mrs. Truth, "if I can just get an hour just for me...." And shared by Ms. Coppin "...I need some time off and they're [adult children] not giving it to me...I can't get anybody to watch my children [referring to grandchildren]". Evident in their statements was the desire to have time for themselves but not having consistent support in their informal and formal social support structures to meet this need. Oftentimes when questioned about what they did in their free time, caregivers expressed "what free time..."! [Mrs. Truth]. Ms. Chinn was one of two grandmother caregivers who created the time and had support from her informal social support network so that she could enjoy her own personal needs. Ms. Chinn shared how her son planned to care for her grandchildren, while she took an overnight trip to Connecticut on Mother's Day with fellow employees,

My son, they're [grandchildren] are going over to Maryland, they leaving tonight. I just finishing talking to him, he picking them up tonight. They going out of here (laughs).

Ms. Chinn was not the only grandmother to create a space for herself. Ms. Moses related creating a space for a personal relationship could be difficult when a person is responsible for rearing grandchildren:

Yes, but you got to carve hard because it's really not a life. That's why I say it takes a strong man to date a woman or say he loves, that's raising her grandchildren. These days and times it takes a strong one. And a lot of times they may want you to go places with them, but you can't. So therefore, he got to be very understanding. And if he's not the understanding type, you might as well forget it. But by him being in God,

God often change a person's ways. So far, he's been faithful. If I say, 'well, come and take me to the market,' and he's not working 'cause he works all the time, he'll say, 'okay, are the kids getting on your nerves?' and when we go shopping, if I got to go shopping for clothes or something, he take the children into another part of the store and he'll deal with them and let me shop.

In summary, all of the grandmother caregivers have functioned at some point during their caregiving experience from both ends of the continuum. Grandmothers did not operate at one end of the continuum in all areas; there was fluidity between the two ends. Some grandmothers operated primarily from one end while others move from one end to the other, depending upon availability of supportive resources. In the final area, a discussion regarding these adaptive strategies and caregiver well-being are addressed.

Survival Strategies and Mental Health

The survival strategies, being strong and self-sacrificing, had a negative emotional reaction, such as over-eating or not eating at all, excessive cigarette smoking, alcohol consumption or emotionally distancing themselves from stressful situations. Mrs. Coppin, who primarily operated from being strong or self-sacrificing, shared the following:

...I don't smoke until about 8:30 or 9:00 at night. And then I sit down and I might want a beer that we had leftover or a glass of wine and a cigarette; and I sit there and read or watch television and I'm happy. That keeps me, ain't no need in worrying about not getting out, going out with my friends that I don't have anymore. But it relaxes me; I just feel that I haven't missed out on anything...it [drinking] doesn't cause me not to get up and do what I have to do in the morning. But before I was dreading getting up in the morning. Now it makes me feel better, I have a better attitude about it. You still gotta do the same things, but it gave me a better attitude.

Mrs. Coppin's family resources were oftentimes unreliable and inconsistent. She primarily relied upon her son and therapist for support. The remaining members in her family were affected by drug abuse, incarceration, poverty and medical conditions. According to Mrs. Coppin, their ability to provide consistent and reliable support was hampered by these conditions. Mrs. Truth's explanation of a possible outcome for grandmother caregivers who primarily operated from this end of the continuum:

... you will eventually crack under the strain and the stress or either you just walk out that door and go to the bar and become an alcoholic...and you drink til you, think you drinking to yourself, easing it, but you're only destroying yourself without even knowing it....

Grandmother caregivers, who had minimal to no supportive resources from informal and/or formal social support, felt they had to be strong, rely solely upon their own internal resources and sacrifice their own needs for the needs of their grandchildren. In doing so, they minimized and neglected their own emotional and health conditions. Mrs. Truth reported that taking care of her grandchildren with minimal support from others interfered with her physical

health. Mrs. Truth was a diabetic and has undergone several laser surgeries to stop her eyes from leaking fluid. Being strong or self-sacrificing required grandmothers to use an enormous amount of internal resources to manage stressors related to their caregiving situation. She related:

You have to be calm and you can't get upset, and it just doesn't help....Sometimes I feel bad, I mean, I get hungry and when I go to eat I gets full up. If I continue eating, I'll get sick. Or my sugar have a tendency to drop drown; its dropped down as low as 30-34. And then it'll just jump back up, Saturday it went up to 205. And then Sunday morning it was down to 179. Then it just dropped right on down to 150, and it'll keep on dropping all day through. Sunday night it was down to 91. And it's just up and down. But the kids come home and act like, don't know which way is up...everybody's trying to talk at the same time. Everybody's telling me what happened. They don't want to talk one at a time...and then they gets angry when I say, 'one at a time, or give me a break, or sit and do your work, we'll talk after while.

Being strong and self-sacrificing required grandmothers to use an enormous amount of internal resources to manage stressors related to their caregiving situation. In the context of their social support structures, grandmother caregivers employed the necessary adaptive strategies in order to meet their caregiving role expectations. Oftentimes, this was done at the expense of their own emotional and physical health. Grandmother caregivers often spoke of being tired, exhausted and frustrated with their caregiving role but at the same time feeling committed to caring for their kin. Mrs. Truth's words echo grandmothers' concerns: "God's always gonna have somebody here to take care of these little ones, somebody. As I said, sometimes, I cry, 'Why'd it have to be me!?'

In summary, grandmother caregivers' coping strategies were primarily influenced by the availability of supportive resources within their informal and formal social support structures. Grandmother caregivers operated from both ends of the continuum depending upon the availability of resources received or not received in a specific area. In the context of their social support structures, grandmother caregivers employed the necessary adaptive strategies in order to meet their caregiving role expectations. Oftentimes, this was done at the expense of their own emotional and physical health. Grandmother caregivers often spoke of being tired, exhausted and frustrated with their caregiving role but at the same time feeling committed to caring for their kin.

Discussion

Prior to discussing these findings, a quote from Jacqueline Jones, author of *Labor of Love*, is necessary to set the stage for the coping strategies employed by grandmother caregivers resulting from "having nothing to fall back on: not maleness, not whiteness, not ladyhood, not anything. And out of profound desolation of [her] reality she may very well have invented herself..." (p. 315). This article examined how older African American grandmother headed households respond when faced with consistent and inconsistent social support from family and community. We use multiple lenses, ecological perspective (Bronfenbrenner, 1979) and the womanist perspective (Collins, 2000), to highlight how caregivers engage in survival strategies and how it affects their emotional and physical well-being. The framework from

which grandmothers engaged in survival strategies was based on their interactions with society, the African American community, family and self. Social conditions influenced the structure of grandmother caregivers' informal social support network and the flow of supportive resources.

These social conditions included death by HIV/AIDS, drug addiction and/or community violence, incarceration, poverty, severe medical conditions, and drug abuse, all of which are disproportionately affecting the African American community. These conditions also affected those who were remaining in the informal supportive network and the type of support grandmother caregivers could receive from these family members. Grandmother caregivers received a majority of their support from family members who were largely unaffected by these conditions. Grandmother caregivers that reported lack of consistent and reliable support from female family members felt they were not providing help because of their drug addiction, medical conditions and/or poverty.

We know from previous studies that grandparent caregivers are overwhelmed with their caregiving responsibilities and may not be receiving support from extended family members (Burton, 1992; Carr, Hayslip & Gray, 2012; Jendrek, 1994; Musil, et al, 2011; Smith, 1994). These studies suggest that the context of caregiving is very important. We provided some insight into how low-income, African American grandmothers from inner-cities are struggling to meet their caregiving demand within fragile communities and families struggling with urban poverty.

We highlight in the context of varying degrees of *reliable* and *unreliable* social support, four themes: *being strong*, *self-sacrificing*, *receiving help* and *self-compassion*. The myth of women *being strong* and meeting the stressors of caregiving in unavailable social support without experiencing physical and psychological detriments to their health and well-being is a lack of understanding the impact of social, economic, and personal issues endured by African American mothers (Collins 1990). Strong black women are portrayed as taking on more responsibility than an average person can handle. They require no help nor do they ask for help. As described in black feminist literature, they are called upon by society to sacrifice their own well-being in order to meet societal expectations (Gillespie, 1984). Glorification of the strong black woman leads to absence or lack of recognition around social, economic and personal issues endured by African American mothers (Hill-Collins, 1990; hooks, 1989; Wallace, 1999). In review of the literature about African American grandmothers, their role of caregiving is often glorified. As observed by Hill-Lubin (1991):

the most visible portrait of the black grandmother in all of the literature is one of action, involvement, hope, and dignity. Although advanced in age, she is not an old woman enjoying the leisure of having no family responsibilities or lamenting that she is nearing death. Most often, she is so busy trying to save others, especially her grandchildren, that she has little time for herself (p. 174).

The role of the African American grandmother being romanticized or idealized in African American communities, is reflective of the "… idea that mothers should live lives of sacrifice…" (Christian, as cited in Hill-Collins, 1990, p. 116). We explored how African American women caregivers fought to preserve their family members often in the context of unavailable social support. We also show that despite their fragile systems of care, there are a few members who are available to provide care. Although studies have examined mental health

and well-being among African-American grandmother caregivers, few studies have explored this phenomenon within the context of informal social support.

Our findings note how the detrimental effects of strength and self-sacrifice coupled with the absence of family and community support puts the grandmother in the precarious position of ignoring her mental and physical well-being. The challenges grandmother caregivers faced were largely dictated by their location in the social hierarchy and concerns expressed by these grandmothers reflected their unique position in society. Primarily because there are African American, female, older and of limited economic independence they are faced with different realities.

Practice Implications

This qualitative study has implications for service providers working with grandmothers from inner cities. Social workers, mental health clinicians, medical professionals and other human services providers must take into consideration the unique circumstances of African American grandparents caring for their grandchildren in our nation's inner cities. With most of them dealing with the loss of their own children and family members to drug addiction, crime, incarceration and/or death within the context of having to parent again in impoverished, crime riddled communities, adds an additional level of stress to an already difficult situation. It will be important that clinicians and human service providers conduct individualized, client specific assessments and develop multilevel interventions to meet the needs of these grandparent caregivers and their grandchildren. These interventions must be implemented in ways that honor and respect the history and culture of grandparent caregiving in the African American community. Realizing that members of this community have engaged in the practice of community self-help, caring for their own, including its children, will enable workers to provide more relevant and culturally sensitive services.

As part of the comprehensive assessment process, clinicians must evaluate the survival strategies used by these African American grandparent caregivers and the level of support, including the informal supports available to them. As with most of the participants in our study, family social support is often limited or unavailable. For this reason, clinicians must work with these parents to identify fictive kin, neighbors, community members, religious congregations and informal social services who can provide some degree of support. For example, service providers or community leaders can work with family members to collectively create a caregiver respite plan for caring of the caregiver. When possible, workers will need to work with the birth parents of the children to provide encouragement, supportive services and referrals in order to empower them to provide some level of support to grandparents. Mental health and counseling services must be offered and encouraged. especially to address the potentially negative impact of "being strong" and "self-sacrificing" behaviors. In order to cease the transmission of these survival strategies from one generation to the next, we must intervene with our elders. This may be possible with connecting the younger generation with the older generation in developing a new script that is gender-specific and culturally responsive to the health and wellness of African American women.

As we contemplate how to best address the issues and concerns related to grandparent caregiving, clinicians will need to "think outside the box" and offer therapeutic sessions in unique ways such as in the home or at local places of worship. Further, it is important family members and service providers pay respect to the rewards of caregiving. Research studies have found grandmothers experience improved health and emotional well-being in their role as

caregivers, including a sense of purpose (Giarrusso, Feng, Wang, & Silverstein, 1996; Hayslip & Smith, 2013; Fuller-Thomson, Serbinski, McCormack, 2014).

In order to transform current caregiving challenges, women must exercise their "voice," that is when individual voices of black women are honored (Collins 2000) and their right to define their own caregiving experiences. Reliance upon extended kin is essential for caregivers to maintain healthy caregiving practices (Simpson, 2009). This can be done when we target interventions to improve structure and functioning of family, including extended family members. This would make it possible for caregivers to engage in healthy caregiving practices within a family context, which would allow them to engage in preventive health-care practices.

Limitations

The findings from this study came from qualitative data obtained from a small sample of African American grandmother caregivers living in a single urban area in the state of Maryland. The west side of Baltimore City where the participants resided is known for its challenges in addressing community violence, drugs, and pockets of poverty. It will therefore be challenging to generalize the findings to African American grandmothers, living in different areas from a different socio-economic status, region, racial and ethnic backgrounds. Readers of this study may be able to link the findings of this research to their own experiences and decide for themselves if it is applicable to their situation. It is important that we better understand how limited social supports impact the mental health of grandparent caregivers and their ability to care for themselves or their grandchildren, as well as how to effectively develop and implement more appropriate services and interventions to best meet their needs.

Conclusion

All grandmother caregivers experienced significant losses in their informal social support network, which was experienced as drain or depletion on their informal social support resources. These losses represent social conditions (e.g. drug abuse, incarceration and urban poverty) which disproportionately affect the African American community. Despite the depletion of resources, grandmother caregivers had at least one reliable person they could call upon in times of need. Family members they primarily relied upon were described as holding working class jobs and having the economic means to provide support. Grandmother caregivers' sons played a major role in assisting caregivers with meeting their needs.

The survival strategies grandmothers employed under inconsistent resources, *being strong* and *self-sacrificing* increases women's susceptibility to mental and physical distress. Grandmother caregivers who operated from this framework acted in this capacity because they were called upon by individuals in their informal and formal structures to cope at this level. It was not considered a maladaptive strategy when faced with limited support from social support structures. It was viewed as an adaptive strategy situated in the context of their current social support structures. In order to move beyond these survival strategies, we must reinforce needed resources desired from informal and formal social support structures.

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Research Article

"If I Don't Take Care of Myself, I Can't Take Care of Them": Exploring Caregiving Grandmothers' Experiences of a 9-Session Self-Care Curriculum

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Abstract

The predominance of research on custodial grandparent caregiving focuses on prevalence, risk factors, and challenges; less attention has been paid to the development of interventions to support this population. In response to a decrease in length of service provision at a local agency, a nine-session self-care curriculum was designed to focus on caregiver health through the empowering, multi-dimensional practice of self-care. The curriculum uses a mind-body approach and was integrated into a pre-existing nine-month support program for grandparents raising grandchildren. Using a basic, interpretive qualitative design, the purpose of this study was to explore how grandparent caregivers: 1) understand and practice self-care in their lives and 2) experienced self-care curriculum introduced within a pre-existing support group. Data were collected though qualitative interviews and analyzed concurrently using basic thematic analysis; techniques used included open and focused coding, cross-checking, and memo-writing. Study findings reveal self-care was most often understood in terms of physical health, caregiving that brought meaning and purpose to one's life, and preferred activities that focused on introspection, solitude, and spirituality. Participants reported the curriculum was helpful, citing benefits such as present-moment awareness, relaxation, and personal connection. Implications for practice and future research are included.

Key words: caregiving, grandmothers, self-care, mind-body, mindfulness, kindship care

Since the 1980s, the prevalence of grandparents raising grandchildren and the circumstances resulting in kinship care have garnered significant attention in the literature. The 2012 US Census (2014) reports approximately 2.7 million grandparent caregivers take primary responsibility for grandchildren under 18 residing with them. Custodial caregiving can yield a multitude of positive outcomes, including providing caregivers with joy, sense of purpose, and the opportunity to parent for a second time with improved skills (Hayslip & Kaminski, 2005; Tang, Jang, & Copeland, 2015). Yet, custodial grandparents tend to be out of sync with same-age peers and often face additional physical, emotional, mental, interpersonal, legal, and financial stressors that can come with the introduction of a new caregiving responsibility (Hayslip & Kaminski, 2005; Langosch, 2012; Tang, et al., 2015; Whitley, Kelley, & Campos, 2011).

Caregiving demands can take a toll on the caregiver, and in recent decades, researchers have extensively examined the health outcomes of kinship care. Caregivers report less engagement in exercise, demonstrate poorer health choices, and participate in fewer health-promoting behaviors than their non-caregiving counterparts (Acton, 2002; Hoffman, Lee, & Mendez-Luck, 2012; Janevic & Connell, 2004). For example, depression is often an emotional and psychological consequence of caregiving (Covinsky et al., 2003; Pinguart & Sorensen, 2003). In fact, Lu and Austrom (2005) report depressed mood in caregivers is associated with negative outcomes such as higher levels of caregiving stress and increased difficulty performing caregiving tasks than those who experience less depressed mood. Pointing to the variation of caregiving experiences, Kim and Schulz (2008) found physical burden and psychological distress are especially prevalent among those caregiving for individuals with dementia, as compared with other caregiving populations. Caregivers often subjugate their own needs in service of the needs of the care recipient, neglecting their own health (Roth, Perkins, Wadley, Temple, & Haley, 2009). Such findings support the notion that an increase in caregiver attention to personal self-care, defined as "a process of purposeful engagement in practices that promote holistic health and well-being of the self" (Lee & Miller, 2013, p. 98), could be helpful in preventing or mitigating negative health outcomes related to the caregiving role.

While the concept of self-care has not appeared much in the caregiving literature, relevant research provides useful direction. For example, studies report stressors related to informal caregiving can be buffered by physical activity (Castro, Wilcox, O'Sullivan, Baumann, & King, 2002; Edenfield & Blumenthal, 2011). To date, the predominance of extant literature on custodial caregiving focuses on prevalence, risk factors, and challenges associated with custodial kinship care, while less attention has been paid to the development of interventions to support grandfamilies and caregivers. However, a reading of the caregiving literature reveals promise of mind-body interventions in

particular, as these efforts may be uniquely suited to address the interconnected aspects of the caregiving experience.

Mind-body interventions can be characterized as those that acknowledge the interaction between the mind, body, and behavior to improve health and well-being (Wieland, Manheimer, Berman, 2001). Interventions taking this approach offer an often absent prioritization of the caregiver's needs and call attention to self-care through present moment awareness. The observation and acceptance of thoughts, feelings, and bodily sensation—whether pleasant or unpleasant—encourages responsiveness rather than reactivity. Such intentionality brings about the consciousness necessary to proactively take steps to improve and maintain health and well-being (Lee et al., 2013). While few have been implemented with grandparents raising grandchildren, mind-body interventions have resulted in positive outcomes with other caregiving populations (Coogle, Brown, Hellerstein, & Rudolph, 2011; Minor, Carlson, Mackenzie, Zernicke, & Jones, L., 2006; Singh et al., 2004; Waelde, Thompson, Gallagher-Thompson, 2004; Whitebird et al., 2012).

Mind-body interventions often incorporate mindfulness, which is understood as "paying attention in a particular way: on purpose, in the present moment, and nonjudgmentally" (Kabat-Zinn, 1994, p. 4). Singh and colleagues (2004) found that caregivers who received mindfulness training were happier and subsequently those being cared for (i.e., individuals with disabilities) were also markedly happier. Mindfulnessbased stress reduction (MBSR) is a mind-body intervention designed to reduce stress through practices such as mindful breathing, body scan, and yoga (Chambers, Gullone, & Allen, 2009), and it has been shown to improve mental health, including depressive and anxiety symptomatology, among family caregivers (Whitebird et al., 2012). Further, Rejeski (2008) advocates for mind-body approaches to gerontological work specifically to attend to physical and psychological challenges often associated with aging. As compared to their non-caregiving peers, custodial grandparent caregivers experience elevated risk for numerous health problems, including psychological distress (e.g., depression) and chronic diseases (e.g., hypertension, diabetes) (Kelly, Whitley, & Campos, 2010). While emerging, research on mind-body approaches with caregivers demonstrates initial success in reducing stress and improving health and well-being in combating strains associated with the caregiving role. Despite the absence of empirical research measuring both self-care and mindfulness concepts, the positive outcomes of mindfulness-based interventions suggest that present-moment awareness may increase the likelihood caregivers will intentionally respond to their experiences by increased engagement in self-care behaviors.

Stressing the importance of attending to the needs of this population in practice, Whitley Kelly, Yorker, and White (1999) advocate for a strengths-based approach to working with custodial caregivers, underscoring the value of emphasizing empowerment and resilience. Interventions taking this approach typically focus on psychoeducation and have proved useful for grandparent caregivers, resulting in increased self-advocacy, life

control, self-efficacy, behavioral changes, and coping skills (Carr, 2011; Cox, 2002; Joslin, 2009). In response to the strong body of evidence that outlines the negative impact of kindship care upon caregiver health, a greater focus on interventions specifically designed to promote self-care behaviors is needed (Langosch, 2012; Tang et al., 2015).

Addressing the Gap with a New Approach: A Self-Care Curriculum for Custodial Caregivers

Service providers at an agency serving older adults located in the southeastern United States approached the researchers to explore innovative ways to support grandparent caregivers in attending to their health and well-being. With funding limitations resulting in a reduction in length of service provision, the agency sought to adapt their pre-existing nine-month program for grandfamilies to enable caregivers to prioritize health through self-care, which can be defined as "a process of purposeful engagement in practices that promote holistic health and well-being of the self" (Lee & Miller, 2013, p. 98). The larger program, which serves four counties, offers a host of services to custodial grandparents including: a monthly support group with childcare, case management, nutrition and exercise education, information and referral services, legal education and services, health screenings and monitoring, and grandfamily activities. Informed by the early literature on both mind-body approaches and self-care, a nine-session self-care curriculum was developed and implemented within the agency's pre-existing program for grandparents raising their grandchildren. A nine-session model was chosen to emphasize self-care across the entirety of the support group program, and the curriculum was developed specifically for this programming. The program includes a rolling admission process; that is, all participants do not enter or exit the program at the same time.

The curriculum aimed to focus on the caregiver's ability to exert agency over personal health and well-being through the multidimensional practice of self-care. The goal of the curriculum was to support caregivers in prioritizing self-care through 1) regular experiential engagement in self-care practices, 2) the introduction of possibly new self-care strategies, and 3) the creation of a culture of self-care in the support group. The curriculum was designed to be integrated into the support group on a monthly basis, excluding summer and December. The group did not meet in the summer, and the December meeting was an end of the year celebration including the children. The nine self-care strategies included were: 1) mindful breathing, 2) progressive muscle relaxation, 3) self-shoulder and neck massage, 4) adequate and restful sleep, 5) stretching and walking, 6) thinking about support systems, 7) gratitude and journaling, 8) music and relaxation, and 9) self-assessment and reflection. The specific practices were chosen to reflect the physiological, psychological, social, and spiritual aspects that influence health and well-being, recognizing the interconnectedness of the mind and body. Consideration was also given to the need for practices to be safe and feasible for caregivers to engage in outside of the group.

Incorporated specifically into the support group element of the kinship care program, the 9-session curriculum was comprised of nine 20-minute sessions aimed at the discussion and practice of different self-care strategies. Undergraduate social work interns and the program coordinator served as facilitators of the curriculum, and these facilitators were consistent across the weeks of the intervention. Facilitators were provided with a guide for implementation, which included an overview of the session, specific steps to follow, benefits of each practice, and a facilitator script. The first 20 minutes of each support group was dedicated to the self-care component, while the remainder of the support group focused on socialization and topics of interest identified by the group members. To illustrate how sessions unfolded, the following describes the progressive muscle relaxation session. First, the facilitator used guiding questions to follow up on the previous session's content to explore how participants are integrating the self-care practice outside of the group. Next, the facilitator provides an overview of the goals and structure of the self-care curriculum; this is intended to continue to reinforce the importance of self-care and ensure all participants understand this portion of the support group, even if previously absent from group. The experiential piece then takes place, accounting for the majority of the session time. Subsequently, the benefits of the practice are discussed, and participants are reminded that case managers will check in with them about how their self-care practice is going outside of group.

The purpose of this research was to explore 1) grandparent caregivers' understanding of experiences with self-care, and 2) participants' experiences of the pilot nine-session self-care curriculum designed to increase custodial grandparent caregivers' attention to and engagement in self-care practices. As such, the study is guided by two research questions:

- 1. How do grandparent caregivers understand and practice self-care in their lives?
- 2. What were grandparent caregivers' perceptions of the self-care curriculum implemented into the support group?

Findings from the present study are intended to support the continued development of this first iteration of the self-care curriculum.

Design and Methods

The present study uses a basic, interpretive qualitative design, which is the most common type of qualitative approach. This methodology was deemed most appropriate given the researchers' goals to understand how caregivers interpret, construct, and assign meaning to their experiences (Merriam & Tisdell, 2015).

Sample Selection and Recruitment

The researchers received support to conduct the study through the agency that provides the program and approval via institutional review board. Participants were recruited using purposive sampling. To ensure confidentiality of clients, staff from the agency contacted all support program participants to determine those interested in the

study; subsequently, staff obtained permission to provide researchers identified caregivers' contact information. Inclusion criteria for the study were as follows: a) participants were custodial caregivers for grandchildren, either formally or informally, and b) participants had attended at least one support group meeting that included the self-care curriculum.

Data Collection

Data was collected using face-to-face, semi-structured interviews based upon a 20-question interview protocol (see Table 1). A 27-item survey was used to gather demographic and personal characteristics, including frequency of engagement in self-care practices measured by the 16-item personal self-care subscale of the Self-Care Practices Scale (SCPS; (Lee, Bride & Miller, 2016; Lee, Miller & Bride, 2017). Using a Likert-scale of 0 (*never*) to 4 (*very often*), the instrument asks respondents to indicate how often they engage in self-care practices spanning physical, emotional, social, spiritual, and leisure domains. Items focus on behaviors such as making healthy nutritional choices, getting adequate sleep, taking action to meet emotional needs, recognizing strengths, being kind to oneself, solving problems when they arise, spending quality time with loved ones, and engaging in spiritual practices. High scores indicate greater frequency in self-care. Reliability analysis suggests good internal validity of the subscale ($\alpha = .883$, n = 512; (Lee et al., 2016; Lee et al., 2017). Interviews ranged in length from 30 to 90 minutes and were digitally recorded with participant permission; one participant opted not to be recorded. A \$25 gift card was provided to thank participants for their time.

Table 1
Semi-Structured Interview Protocol Questions to Address Research Questions

Research Question 1: How do grandparent caregivers understand and experience selfcare in their lives?

- 1. What is your understanding of "self-care?" what does it mean to you?
- 2. For you, what does your self-care look like? How do you take care of yourself?
- 3. What motivates you to take care of yourself?
- 4. What have you noticed are the benefits of taking care of yourself for you?
- 5. What would it look like if you could have more self-care?
- 6. How could you go about adding more self-care to your life?
- 7. What would you have to do differently to make this happen?
- 8. What are challenges to taking care of yourself?
- 9. What would you need to be in place to help with these challenges?

Research Question 2: How did grandparent caregivers experience the self-care curriculum implemented into the support group?

- 1. What do you remember about the self-care part of the support group?
- 2. What did you think about the self-care part of the support group?
- 3. What did you like most about the self-care part of the support group?
- 4. Which, if any, self-care activities did you find helpful in the support group?
 - a. How were they helpful?
- 5. Which, if any, self-care activities that you learned in the group have you been doing outside of group?
 - a. How often?
- 6. Which, if any, self-care activities in the group that you would not use on your own?
 - a. Could you tell me more about that?
- 7. Are there any other self-care strategies you would like to see included into the group?
- 8. What, if anything, did you learn about through the self-care focus of the group that you didn't know before?
- 9. Did your caseworker check in on you and your self-care plan?
 - a. What was useful about this check-in?
 - b. How could this be improved?
- 10. How could this program support you in taking care of yourself?
 - a. In the support group?
 - b. In the program in general?

How could the program support you in taking better care of yourself outside of the support group?

Sample

A total of 14 possible participants meeting the above criteria were identified through recruitment procedures. Two grandmothers could not be reached, and one was unavailable due to time constraints. Eleven grandmothers were interviewed, and one interview was excluded from data analysis due to limitations in the caregiver's cognitive capacity to respond to interview questions. All participants were in the same group; the total number of participants per session is unavailable. Demographic and personal characteristics of participants are displayed in Table 2; pseudonyms are used to protect participants' confidentiality. All participants were female, and of the 10 participants, seven identified as Black / African American, two White/Caucasian, and one chose not to identify her race. Participants ranged from 41 to 70 in age, with a mean age of 58.5. The highest level of education completed ranged from high school to graduate school, and most participants did not work outside of the home. When asked to rate their overall health using a five-point Likert-scale (0 = poor – 4 = excellent), most participants reported *fair* (1) or *good* (2) health. The Self-Care Practices Scale scores ranged from 31 to 52, with a mean score of 40.2. Participants' attendance varied from three to nine

sessions. The rolling admission design of the program did not allow for selection of a cohort of participants who could participate in the entire curriculum. However, the ninemonth period of curriculum implementation did allow for any participants present to experience the curriculum together.

Data Analysis

Transcripts derived from digital recordings and researcher notes from the interviews yielded data across the cases. As suggested by Merriam and Tisdell (2015), data were collected and analyzed concurrently, using basic thematic analysis. After the completion of all interviews and transcription, the initial reading of transcripts involved open-coding procedures; the two-person research team independently reviewed transcripts and derived initial codes. As suggested by Creswell (2009), this cross-checking method utilizing independently derived results strengthens the reliability of study findings. Focused-coding, the practice of using the most significant and frequent codes to examine and analyze data (Charmaz, 2014) was then used to narrow data most relevant to the research questions. Memo-writing was used to help the authors shift from categorizing to

Table 2
Participant Demographics and Personal Characteristics

Participant	Age	Race / Ethnicity	Highest Level of Education	Work Outside of Home	Health Status	SCPS Score (range = 0-64)	Sessions Attended
Beverly	46	White/ Caucasian	GED	No	Fair	31	4
Natalie	60	Black/African American	Some College	No	Fair	33	7
Anita	60	Black/African American	High School	No	Fair	34	3
Shirley	41	Black/African American	11 th grade	No	Good	34	7
Harriet	56	White/ Caucasian	GED	Yes	Fair	35	4
Yolanda	69	Declined to answer	Some College	No	Fair/ Good	40	5
Gladdis	67	Black/African American	High School	No	Good	44	7
Phyllis	65	Native American Black/African American	Bachelor Degree	No	Very Good	49	4

Maureen	50	Black/African	9 th grade	No	Fair	50	6
Gail	70	American Black/African American	Master Degree	No	Good	52	9

interpreting the data following the aforementioned coding procedures (Creswell, 2009).

Findings

Caregivers' understanding and practice self-care in their lives as well as their perception of the self-care curriculum are presented in the following section. Themes derived from the data are organized by research question (RO).

RQ 1: Understanding and Practice of Self-Care

Conceptual Emphasis on Physical Health. When asked to define or provide their understanding of self-care, most participants discussed the concept singularly in terms of physical strategies. References to diet, sleep, and medication were most commonly included in responses. Yolanda, a 69-year-old grandmother who has been caring for her 18-year-old granddaughter for about seven years, explains what self-care means to her, "There is an element of exercise. There is an element of taking care of you in a physical sense. As you grow older, [...] things become a case of being able to take care of yourself, literally." Phyllis, a 65-year-old grandmother of two grandchildren (ages 4 and 13), has been a caregiver for two years. Similar to Yolanda, she focuses on the importance of dietary habits and safety, noting, "[Self-care means] being healthy, taking care of my body, doing the right [thing], eat the right stuff. I guess trying to be safe [...] just stay focused. Get a lot of sleep, drink water more than other stuff." Gail (age 70), custodial caregiver to three grandchildren (ages 13, 19, and 22), adds:

Basically, for me, I need to get the proper sleep, and I need to lay in bed until about 9 'cause I get up around 5 o'clock or somewhere in there, and I try to, you know, organize the children where I won't have to stress in the mornings.

Avoidance of health-impeding behaviors was also mentioned. Harriet, the youngest of the caregivers interviewed, said, "I'm in the process of quitting these [points to cigarettes]. I have no choice but to quit and lay my cigarettes down. Right now, I'm on medication to help me stop smoking." At 50, Maureen has been for caring for your five grandchildren for nine years. She emphasized the importance of weight control, exercise, and healthy eating.

Caregiving Provides Motivation and Purpose. For participants in the present study, the caregiving role itself served as a primary motivation for self-care. Shirley (age 56) summarized the sentiment with her statement, "In order for us to see about our grandkids, we got to see about ourselves. So, that's what self-care means to me." Anita expressed a similar idea, "You have to take care of yourself in order to take care of our kids, cause if you don't take care of yourself, you can't take care of them. You'll be lacking in some way." Phyllis commented, "I love them. I can't imagine them being anywhere else. I wouldn't want anyone else to have them, not even their mama [...]. It [caregiving] keeps you motivated, keeps you moving."

The notion that caregiving benefits participants' well-being was apparent as caregivers talked about the sense of purpose they have in raising their grandchildren. Phyllis commented,

I think it [caregiving] gives you something to live for [...] I wouldn't feel right if [my grandchildren] had to go to a foster home, so I'm just thankful that they can come here and be safe and cared for.

Natalie, age 60, comments,

They keep me laughing and keep me going. There's no negative side to it. [...] Some days I don't feel like doing anything, but you know, I have to keep going because of the kids. They would be my motivation.

In fact, caregiving was even considered a primary source of fulfillment. Harriet explains,

My grandkids—yep, I think that's one of my purposes because they love me, and I love them. [...] They're what makes me want to keep going, because I just can't see no other way of somebody taking care of them or something. As far as me taking care of them, I just want to make sure everything is right, full of love, giving them attention.

Solitude and Introspection. When participants described activities they engaged in to take care of themselves, a theme of solitude and introspection emerged. Related self-care practices included deep breathing, quiet/alone time, journaling, relaxing and/or listening to gospel music, and reading. Natalie explains how she uses many of these strategies, "Listen to music and just while I'm listening, doing the breathing. I do that and just go off, have free time. Go to the room by myself and sit there and listen to my music and just relax."

Positivity. Several of the grandparents describe various practices intended to cultivate positivity as a means of taking care of themselves. Gladdis, a 67-year-old caregiver, suggests, "Positive thinking. Be positive—it's the best way to go." Similarly,

Beverly, age 46 and caregiver to two young grandchildren, reflects on how focusing on the good things in her life helps her. She recalls:

When you start to write in your journal you think of more positive than negatives, so it makes you feel better. And you know there's a reason for everything. When you start writing all your positives down, you know that there's a good reason they're here with us.

Spirituality. Almost all participants described spirituality as an important aspect of their self-care practice. Prayer, the reading of religious texts, and meditation were the behaviors mentioned that contribute to this theme. Engagement in spiritual practices appeared central to managing various stressors (e.g., parenting, financial strain) and garnering strength, hopefulness, and gratitude. Beverly describes the helpfulness of spirituality in relation to the challenging aspects of parenting:

It helps because if I didn't pray, there's no telling what kind of emotional [state] [...] I would be in because I have really bad nerves, really bad and I do take medicine for it. But with the grandkids they really know what buttons to push. Every morning I pray that it is a good day.

Likewise, Anita, a 60-year-old caregiver, viewed spirituality as a way to deal with the frustration accompanying caregiving. She states,

I mean it [prayer and meditation] helps 'cause I know strength that I have —it comes from above. It comes from God. [...] Stressful times, you know, when you know how kids are - teach you to be patient sometimes and blow your top but if you pray and meditate, it helps keep from blowing your top.

Emphasizing the strength spiritual practice provides, Gail comments,

It's a difficult task; it's not easy, and you know I have to pray and have to read my bible. I have to pray for myself; I have to pray for them—pray for her [the participant's daughter and children's mother]. You know, I couldn't do it without God, I just couldn't cause I would be all out of sorts.

Harriet explains, "I like to read spiritual stuff and anything to boost my spirit or hopes or increase my faith or make me think differently." Shirley describes how spirituality promotes persistence:

I just try to make things work out the best way I can, and I've been doing good. I thank God for that because every day you be wondering how you're going to make it, and then with prayer, things work out.

RQ2: Perception of the Self-Care Curriculum

By and large, caregivers spoke of the usefulness of the self-care curriculum, both in the group and in their personal lives. General positive comments about the curriculum include Shirley's assertion: "I've been feeling better since I just do some of the things that they told me." Anita commented, "It helped in the way they [...] a lot of times you're raising kids, grandkids, it's stressful and to take time for yourself to do the exercises that will relax you—it helps." Gladys noted, "It was very helpful we had demonstration, and it was very helpful and relaxing. [...] If they had grandchildren to raise, I would advise anybody to join it."

Some caregivers expressed that they had learned new self-care strategies. Beverly shared what she gained from the curriculum with her statement, "I learned they [self-care strategies] help. They're good to do and good to know, especially in times when you're really stressed." Shirley expressed a similar sentiment, stressing the usefulness of the strategies outside of the group in her statement,

Before you get into the program, you don't know anything about a lot of stuff and by them giving me info on a lot of the help, self-care techniques [...] it was helpful because I began to use them.

For others, the value of the curriculum was less in education about new practices, but rather in the prioritization of self-care and motivation that the group offered. Natalie explains,

It's not about not knowing [what self-care is], it's just about not doing it or taking the time to do it. I know the breathing exercises can relax you. [...] Just when I go to group and when we do it, it reminds me that I need to think about me sometimes too and focus on me so that I can be better, and that's what, you know, keeps me going when I'm there. It helps remind me of the things that I need to do to take care of myself.

Yolanda stated, "I think [the practice of self-care exercises] are good because it's very hard to be self-motivated in that area." Similarly, Shirley shared, "Some people like me need that little push, that motivation—that encouragement, and if they offer it, I'm pretty sure we will do it."

Present Moment Awareness. Of the nine strategies included in the curriculum, mindful breathing was most often mentioned in participants' reflections. Caregivers described how present moment awareness, cultivated through breathing or other practices, served as a means of decompression and, at times, a way to disengage and appreciate solitude. When asked what was memorable about the curriculum, Shirley responded,

The breathing part – that right there was what really stood out. Just kind of take a quiet time. That right there seemed to help a lot. [...] So when we done that, it was just like a big load of tension had been lifted. That's how it felt. [...] It calmed and relaxed me.

Like others, she went on to describe other benefits of this practice in stating,

I never thought about sitting down and taking deep breaths and getting my mind right, because I was always racing and always moving as you can kind of see. I go to bed moving and wake up moving, so I just never took that time to even think about breathing or never took that time I just need for myself. And you know they say either like ten or fifteen minutes is good. I just never thought about it. I just thought I never had time, so it all helps out; it works.

Phyllis described, "You know how you can massage your shoulders and all that to get your problems out and just focus on the moment, so I liked that."

Relaxation. Nearly all participants described valuing the self-care portion of the group experience because of the identified benefit of relaxation. Harriet even commented on the impact of including the curriculum at the start of the group, noting, "It made it kind of open you up and relaxed you more, that way you could listen better and respond better." Phyllis described how she used mindful breathing outside of group to reap this benefit. She stated,

The breathing, taking time, and you know, taking time for yourself if it isn't but 10 minutes a day or whatever to actually just to go a quiet place and be able to calm down [...] Raising grandchildren isn't easy and you get overwhelmed. Even if it's just going to another room for 10 minutes to calm down, to gather your thoughts.

Connection. While interview questions were specific to the self-care content of the support group, most participants described the importance of the group itself, fellowship with other caregivers, and the availability, attention, and support of the staff. Engaging in the curriculum (and support group) alongside others served as a means of self-care, perhaps promoting caregivers' continued involvement and commitment in the group.

A few caregivers noted connection with other caregivers and staff was encouraging and a means of decreasing feelings of isolation. Gail commented,

Sometimes you feel like you're the only one that's going through stuff but you're not. [...] The telephone calls are very encouraging because you know somebody

else outside of the family cares about you, and that's very important because in taking care of the grandchildren, they don't seem to appreciate what you do for them. [...] That's very supportive to me. Just a phone call.

Inspired by other caregivers, Beverly describes the importance of connection. She noted, Just knowing that you're not the only one in that situation. [...] I don't consider myself very old, but there are a lot of women there that are a lot older than me, and I just sit and wonder 'How did they do this?' 'Cause I think some of them are like great-grandparents, makes me wonder. There's one lady there, she's got like 4 of her grandkids and she's just as jolly as can be. I'm like, I want to be like that.

Others noted their relationships with fellow caregivers outside of group and thoughtfulness of the staff checking in with them. Yolanda indicated the emotional benefits of this aspect:

That's an important part of it. It's the socialization, being able to present what are our issues and hear that we're not alone. And our case may not be the worst, may not be the best, but it can get you out of that self-pity mode that will always lead us down a downward slope. That's something we can always use—that little mental boost.

Finally, participants were invited to comment on any changes or additions to the curriculum they believed would be beneficial. Many people did not have any particular suggestions, but several participants requested the continuation of the mindful breathing. Yoga, meditation, nutrition, more exercise, different ways of breathing for relaxation, and a spa day were suggested for future iterations of the curriculum.

Limitations and Discussion

The present study was designed to ascertain custodial grandparents' understanding and practice of self-care as well as their experience as participants in a nine-session self-care curriculum implemented into a pre-existing support group. Grandparents' conceptualization of self-care was predominantly defined by physical health, and caregiving provided motivation and a sense of purpose for caregivers. Themes defining the most common self-care practices were solitude and introspection, positivity, and spirituality. The curriculum was reported to be very beneficial to caregivers, and the most salient elements noted were present-moment awareness, relaxation, and connection.

As with any research, findings from the present study should be considered in the context of its limitations. The qualitative methodology, small sample size, and lack of geographic variability present threats to external validity. Given that data were self-reported, bias or social desirability could be limitations. As is often the case with support group interventions, attendance was variable, and while attendance was generally strong

and consistent, this irregularity does present a limitation for interpretation. While the interview protocol invited participants to reflect solely on the self-care curriculum, isolating this aspect of the program could be challenging for participants, therefore potentially influencing or limiting the evaluative nature of feedback provided.

Related, the rolling admission of participants prevented a cohort-model of program completion, resulting in all nine sessions being unavailable to all participants. The number of intervention sessions attended varied by each participant. Though unavoidable given the design of the program, this aspect does limit evaluation of the self-care curriculum. Further, logistical limitations prevented the collection of pretest quantifiable health outcome data, making it difficult to determine if the posttest data available (e.g., SCPS scores) was a direct result of the intervention. Similarly, data regarding the frequency and nature of check-ins with the case managers is unavailable at this time. Despite these limitations, the present study can be useful in the development and implementation of future interventions as well as alternation of pre-existing programming, particularly in light of the dearth of intervention research focused on self-care programming for caregivers.

Findings provide implications for the development and implementation of interventions targeting health behaviors of grandparent caregivers. Participants reported that the curriculum offered benefits beyond physical health and even engaged in practices that attended to other aspects of self-care, yet caregivers defined self-care narrowly. Grandparents' perception of self-care was predominantly concerning physical health, and caregivers may benefit from increased education related to the other dimensions of self-care. Lee and Miller (2013) propose a conceptual framework that suggests personal self-care is supported by five "structures of support" (p. 99), which are domains capturing self-care practices aimed at attending to needs in a holistic sense. Incorporating a broader, multi-dimensional understanding of self-care, like the one offered by Lee and Miller, may result in caregivers seeking increased support for the emotional, social, leisure, and possibly spiritual realms of self-care. Intentionally prioritizing caring for oneself across these domains may have greater impact than a more reductionist perspective of health (Lee et al., 2013).

In addition, emphasis on self-care practices that cultivate solitude, introspection, relaxation, and spiritualty may be particularly beneficial to custodial grandparent caregivers. The curriculum also brought forth the importance of stress reduction and social support in taking care of oneself. Consequently, attending specifically to stress reduction and taking steps to build rapport between clients and workers, as well as amongst peers, may also be particularly helpful for caregivers. Finally, attending to the specific challenges of this population offers important considerations for practice (e.g., time constraints often reported by caregivers, lack of transportation, or other causes of absenteeism).

Findings lend support to the notion that interventions aimed at increasing selfcare, particularly if inclusive of mindfulness-based strategies, may be promising. A

bourgeoning line of inquiry examines mindfulness-based interventions with older adults and caregiving populations. For example, mindfulness-based interventions used with caregivers of those with dementia have been effective in reducing stress and anxiety and improving emotional functioning and well-being (Waelde et al., 2004; Whitebird et al., 2012). Similarly, such interventions have been shown to decrease in stress symptoms and mood disturbance in older adults reporting clinically significant depression and anxiety (Splevins, Smith, & Simpson, 2009; Young & Baime, 2010), caregivers of children with chronic conditions (Minor et al., 2006), and those providing care to people with Alzheimer's (Coogle et al., 2011). Mindfulness practice positions caregivers to be responsive (versus reactive) to the range of thoughts, feelings, and sensations that can accompany the caregiving role, any or all of which can be complicated in the context of aging. Mindfulness encourages personal agency, recognition of strengths, and proactive attention to one's health and well-being; these outcomes are consistent with the strengths-based (Whitley et al., 1999) and empowerment approaches (Whitley et al., 2011) advocated for in practice with caregivers.

Future Directions

Continued evaluation of the present intervention would strengthen support for its use. Standardized instrumentation to measure self-care, specifically in the context of caregiving, is needed to assess intervention efficacy more rigorously. Replication studies including various caregiving groups would cultivate a more nuanced understanding of the variables that may impact positive outcomes for each population. Given the short length of the sessions developed, the presented model would be more appropriate for preexisting groups than as an independent curriculum. However, the intervention content could serve as a starting point to develop a standalone curriculum if the context of service provision makes a more intensive self-care intervention feasible. Given the scarcity of mind-body approaches for caregivers—and custodial grandparent caregivers in particular—continued development and evaluation of interventions grounded by these approaches would make a meaningful contribution to practice and research.

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Practice Brief

Example 2.1 Kinship Care and Communication: Family Portraits Project - Helping Teens Tell their Stories¹¹

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Abstract

This practice brief focuses on the importance of communication within the kinship family with particular emphasis on the challenging teen years. It highlights information on the changes impacting relationships within kinship families as children age. This brief includes details about the *Family Portraits Project*, a specific and easy to replicate intergenerational project designed to enhance communication in kinship families.

Keywords: kinship care, art therapy, intergenerational caregiving

The Relatives as Parents Program (RAPP), funded by the Brookdale Foundation, and which has operated through the Cornell Cooperative Extension in Orange County, NY since 1998, is designed to assist grandparents and other relatives who have taken on the parenting role. As a program with an intergenerational focus, the needs of the entire family are addressed. Through formal surveys and anecdotal feedback gleaned from adult and youth participants, we have learned the importance of providing an environment where family members can come together to build a sense of belonging and community, assist in the development of personal and social skills, and recognize the strengths of their new family. One essential element of the family environment is promoting enhanced

¹ An earlier version of this article's content can be found at: http://citeseerx.ist.psu.edu/viewdoc/download;jsessionid=D53D06301059C5C16267E7F4272C13 D1?doi=10.1.1.400.5890&rep=rep1&type=pdf

communication between kinship caregivers and the children in their care. This brief focuses on the importance of communication within the kinship family, with emphasis on the challenging teen years. It contains details about a specific intergenerational project designed to enhance family communication, entitled the *Family Portraits Project*. The program includes 119 kinship families residing in Orange County, NY. Most families participating in the program had been involved with RAPP for several years. While the program was well received by families with school age children, families with teens also found the *Family Portraits Project* to be an excellent tool for enhancing their interpersonal communication. Teens, working cooperatively with their peers and caregivers, used this tool to explore their families' histories and to confidently tell their own stories. The youth voices clearly suggest the positive impact of this project,

"This is the best thing I have ever done. It makes me think that my family is right in front of me. ...still in my life."

—Timothy, RAPP youth

"It has helped me look at my family history. Now when I grow up I won't forget it, because it will be right there for me."

— Adam, RAPP teen

Background

Communication, while important for families with children of all ages, is especially challenging with teenagers in the family. Grandparents report increased difficulties parenting their grandchildren as these children get older. Research from Moore, Hatcher, Vandivere, and Brown (1999) confirmed that the teenage years are particularly challenging with regards to communication involving discipline for families in which grandparents are raising grandchildren, especially in families with older grandparents who tire more easily or have potentially outdated views on parenting. Common communication issues raised by both grandparents and grandchildren are:

- Difficulties relating to each other due to a generation gap, in which grandparents are perceived to have unreasonable guidelines related to clothing, rules, and dating, as well as a perception that the grandparents are unduly strict.
- Grandparents often feel that children today are not as receptive to their rules as they were in the past and that society at large is more lenient than they are accustomed.

These communication differences create difficulties on the part of the grandparent to develop and enforce realistic discipline strategies, and to accept discipline from the grandparents. Support, education, and communication help bridge these gaps and potentially reduce risky behaviors among teens

Research also suggest, older teens require more monitoring, report lower relationship quality with their grandparent receive less positive parenting, and have fewer family routines than do younger teens (Dunifon & Kopko, 2012). These findings suggest that grandparents need support and strategies to help them to remain involved in their teen's lives in a developmentally appropriate way.

Teens being raised by their grandparents also develop an increased awareness of the complexities of their living situation. They may have questions about their parents' past behavior and current role in their lives. They may also compare themselves to friends who are not being raised by their grandparents. A stage of adolescent development is establishing identity and considering one's role in the context of the family and peer network. This is a tall order for all teens, but teens being raised by grandparents face special challenges. For such teens, the identity-formation process includes thinking through why and how they came to live with their grandparent, what role their parent may play in their lives, and how they tell that story to themselves and to others.

Many teens being raised by grandparents have ongoing relationships with their parents, but find these relationships to be challenging. Dolbin-MacNab and Keiley (2009) found that a substantial group of teens (20%) refused to talk about their parents in a study, because many found it to be too distressing. These findings are all indications of the complex feelings some teens raised by grandparents have about their parents. Research further shows that when teens have a difficult relationship with their parents, their relationship with the grandparent can suffer with relationships of poor quality, more feelings of anger, lower family attachment, and less effective communication and parenting strategies (Dunifon & Kopko, 2012). Despite these challenges, many teens raised by grandparents report strong emotional bonds and warm interactions with their grandparents, as well as feelings of respect and gratitude that increase as children enter adulthood. Furthermore, grandparents raising grandchildren demonstrate high levels of warmth as well as an increased maturity and perspective that accompanies raising children for a second time.

Family Portraits Project Overview

Given the unique situations of kinship families, the need for opportunities to "tell stories" is a useful communication strategy for both teens and their caregivers. Unfortunately, however, teens are not always enthusiastic about sharing their thoughts, feelings, and intentions with the adults in their lives, especially when these thoughts and feelings involve their birth parents and difficult past histories. Current research on grandparents raising their grandchildren, as well as guidelines for implementing a

successful *Family Portraits Project* series to support the development of positive communication and strengthened family dynamics in such families, help to frame the described practice approach.

The adolescent development process, combined with teens increasing awareness about their unique living situation, highlight the need for efforts such as the *Family Portraits Project*, a creative family project that naturally opens the channels of communication. The program is a six to ten session series using art, writing, photography, and computer technology to develop a personal family book. The aim is to provide youth in kinship care with a safe, fun, and educational way to explore their family dynamics and history, while improving communication with their caregivers. It focuses on the creative process of storytelling as a vehicle for self-expression. Group discussions during each session provide opportunities for connecting with peers while take-home prompts allow for storytelling and intentional information-gathering at home. Through this process, each participant creates an individual book to take home and share with their family and friends.

Family Portraits Project Goals

The goals of the *Family Portraits Project* encompass emotional, academic, and social outcomes. Creating a family portrait allows participants to:

- Develop creative strategies for dealing with emotions and expand abilities to communicate emotions
- Hear and witness peer and adult support systems
- Develop peer relationships and interpersonal skills
- Improve family attachment and communication
- Achieve insight and personal/ family growth
- Work collaboratively during group discussions and develop feelings of camaraderie. Improve self-esteem and discover talents
- Improve perseverance through long-term commitment to their project
- Develop problem-solving and organizational skills, including ability to differentiate when to ask for support and when to work independently
- Improve 21st century technology skills through use of digital photography and various computer programs

Family Portrait Action Steps

The main action steps for implementing a *Family Portrait Project* are described below. The noted steps are flexible and may be adapted to best meet the needs of family members. .

• *Introduction* - Initially families are introduced to the project and informed that they will be asked to make a commitment to participate regularly. Consistent attendance throughout this project enhances group cohesion and promotes successful completion. Ideally groups should be limited to 10 families with each

session allowing for one hour of artmaking and additional time for clean-up, snack, and discussion. Anecdotal evidence suggests that youth ages 7 and up have been most successful in this model. It was found that younger children did not have the cognitive ability for long-term planning, computer skills needed, or understanding of some prompts.

- Story Reading Next, a book about unique family structures is read to and discussed with the group to help open communication, break down barriers, and build community. Love is a Family by Roma Downey is one example of an effective story used in this context.
- Former Stories Families are shown books that previous Family Portraits Project participants have created (or examples created by the staff) and are afforded opportunities to ask questions, express concerns, and discuss their willingness to fully participate. Providers are encouraged to create a personal book prior to starting this project to familiarize themselves with the process.
- Selecting Book Topics During the first session, families are asked to review the list of possible book pages together and spend time as a family talking and taking notes about the topics. Some of the page prompts include: The day I was born, Something you should know about me, The family member I am most like is,,, (See Appendix for a comprehensive listing of topic prompts). Participants are encouraged to have fun discussing family memories, history, and legacy and to consider using different prompts to fuel dinnertime conversations or in place of TV time.
- Family Memories Families are also encouraged to begin taking photos, as well as collecting family photos and other documentation, to help guide the process and encourage communication and creativity. Families who do not have access to a camera at home are provided with a disposable camera to use for taking new photographs.
- *Teen Groups* Each session, the teens meet as a group for a discussion about the "topic of the week" which relates to one of the page prompts. For example, the group members might share "what I learned about my family," "what my family looks like," "what I really love about my family," or "my family's biggest challenge." They then will complete one page of their book using various art materials, writing, and/or photos to illustrate their reactions and expression about the topic or prompt.

• Listen and Share - Through this group process, participants utilize opportunities to listen to others who are like them and share thoughts and feelings about their family that they may not feel comfortable doing elsewhere. Beginning with their peers, the act of being heard and witnessed can be enough to open the door for continued communication outside of the group. Further, the multimodal opportunities for self-expression (through photos, art, books, and discussion) enable even the most nonverbal teens to explore and share their emotions.

- Caregiver Groups While the teens are meeting, caregivers converse during support group about similar topics and their success or challenge in communicating with their teens. After these separate meetings, caregivers and teens join to work collaboratively on book pages or themes to include in the final book.
- Book Compilation Once participants have created their book pages, they begin to compile their books using digital images of their artwork and computer technology to produce a bound book composed of their artwork, photos, and writing about their creative expressions.
- Book Gallery The project then culminates with a "gallery of books" where participants are presented with their books and encouraged to share them with one another. Families are able to take these books home to keep and reflect on throughout the years as their "family portrait" changes.

Conclusion

While relationships between teens and caregivers can be complicated, most grandparent caregivers have an exceptional gift in being able to share their family history and build a lasting legacy. The benefits of this exploration reach not only teens and caregivers, but also family members near and far working to bridge the gaps that exist in these complex family portraits. The *Family Portraits Project* gives families permission to embrace their differences while developing the positive communication skills so critical in the risky teen years.

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Appendix Family Portraits Project: Sample Page Prompts

Below is a listing of sample prompts that may be used by family members to assist in creating their family portraits. Page prompts may be adapted to meet family needs.

The day I was born
Something you should know about me
The family member I am most like is
What makes me unique in my family
How I see myself vs. H\how my family sees me
Family shield
Our family tree
Visual timeline of our family
My invention to make my world a better place
What HOME feels like to me
The best thing about (family member name)
Me at age(caregiver at same age as child)
The best & worst thing about being years old.
Self Portrait Page
Our favorite family activity
Favorite family recipe

Policy Brief

Federal and State Advances to Support Grandfamilies

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Abstract

Grand Voices have been front and center at the nation's Capitol inspiring law makers to enact reform during an uncertain time. Activity has been frenetic in Washington, with a new Administration, repeated efforts to repeal the Affordable Care Act and several natural disasters demanding attention. Despite distracted law makers, several committed members of Congress have forged ahead on reforms specifically for grandfamilies, thanks in significant part to a new initiative of Generations United and Casey Family Programs, called GrAND Voices. GrAND Voices are caregiver advocates from around the country who elevate their voices, bringing their personal experience raising relatives, in addition to those they work with, to the attention of lawmakers. GrAND Voices were an integral part of the 5th national GrandRally in Washington, D.C., and have inspired new legislation. They have helped elevate the need for supports and services to grandfamilies in light of the opioid crisis and the increased numbers of children they are raising. The crisis has provided an urgent platform for pursuing reforms such as providing preventative services to grandfamilies and implementing the Model Family Foster Home Licensing Standards. Improved foster care data collection and a 2016 federal court case also have implications for those grandfamilies who have child welfare involvement. On the state level, many jurisdictions continue to try to make inroads for grandfamilies by implementing policy changes, such as new guardianship assistance programs. Grandfamilies support is moving in the right direction, albeit slowly.

Keywords: Grandfamilies, Kinship Care, Policy, Federal, State, Child Welfare, Temporary Assistance for Needy Families, Family Foster Home Licensing

GrAND Voices have been front and center at the nation's Capitol inspiring law makers to enact reforms during a particularly frenetic time with many new challenges to address. Thanks to the GrAND Voices' efforts at the 5th National GrandRally, meetings

with members of Congress, and their staff, and testimony during a Congressional hearing, legislation to help the families both inside and outside the foster care system is being pursued. In addition to legislation in Congress, the other two branches of government also have significant activity that could help many grandfamilies. There is an important federal circuit case that should result in equity between relatives caring for children in the foster care system and non-relative foster parents in Kentucky and Ohio. New federal data collection will also give us important new information about grandfamilies inside the child welfare system. The states are busy enacting reforms to help all grandfamilies. More jurisdictions are taking the option to use federal child welfare monies to provide guardianship assistance programs for those children exiting foster care with a loving relative, and caregiver means-testing for TANF child-only grants in Washington State has finally been repealed. The states, in addition to the federal government, are responding to the opioid crisis and the resulting increase in number of grandfamilies with important supports. Although much remains to be done, progress is happening, thanks in large part to the elevated voices of the caregivers themselves.

GrAND Voices

A few years ago, Generations United and the Casey Family Programs launched the Grandfamilies Advocacy Network Demonstration (GrAND). GrAND Voices consist of a select group of kinship caregivers with wide expertise and personal experience as relatives who have raised children when their parents have been unable to raise them. GrAND Voices currently represent 35 states, with plans to expand to include all states. A complementary initiative supported by the W.K. Kellogg Foundation will further expand the network with an additional 25 caregivers specifically focused on elevating issues impacting African American and Native American grandfamilies.

Grand Voices have been instrumental in recent federal advances for grandfamilies. They have helped Generations United in all its work on behalf of the families. They have eloquently spoke about their need for support during the 5th National GrandRally, testified at a Congressional hearing, met with individual members of Congress and their staff about the families' strengths and challenges, and inspired legislation to help the families.

Federal Response to Grandfamilies and the Opioid Crisis

Generations United released its 2016 State of Grandfamilies Report on *Raising the Children of the Opioid Epidemic: Solutions and Supports for Grandfamilies*. That report, in turn, provided the background and inspiration for a Senate Aging Committee hearing in March 2017 called *Grandparents to the Rescue: Raising Grandchildren in the Opioid Crisis and Beyond*. The hearing, which featured testimony from Generations United's Deputy Director and two members of GrAND Voices, helped motivate members of Congress and others to support the children and caregivers in these families. A direct result of that hearing was new bipartisan legislation.

FEDERAL

Supporting Grandparents Raising Grandchildren Act

After the opioid hearing, Senators Susan Collins (R-ME) and Bob Casey (D-PA) introduced the Supporting Grandparents Raising Grandchildren Act, S. 1091. A companion House bill, H.R. 3105, was also introduced by Representatives James McGovern (D-MA) and Peter King (R-NY). This legislation would create a federal task force charged with developing and disseminating information to help grandparents and other relatives raising children. The task force would also be responsible for producing two reports to Congress on best practices to support these caregivers and any identified gaps in their resource needs. This legislation, if enacted, would help coordinate federal resources for grandfamilies.

Family First Prevention Services Act

GrAND Voices have also spoken of the need for preventative services and supports, which are addressed in The Family First Prevention Services Act. That bill is landmark child welfare legislation with six titles addressing an array of services and programs. In 2016, it (H.R. 5456) passed the House of Representatives, but the Senate failed to enact it after significant opposition from a few states and primarily their group foster care home providers.

The bill in its entirety was reintroduced in the House in 2017, known as H.R. 253, but it has stalled. Several pieces of the legislation are specifically important for grandfamilies:

- Allows for federal reimbursement for prevention services and programs

 For the first time, this Act will allow federal child welfare dollars to be used on services and programs to prevent children from entering foster care by supporting the triad of generations in grandfamilies -children, kinship caregivers and parents. The children can get services if they are "candidates" for foster care who are at imminent risk of entering care and can safely remain at home with parents or with kinship caregivers. Kinship caregivers or parents of these children can also get services if they are needed to prevent the children's entry into care. These prevention services and programs include mental health treatment, substance abuse prevention and treatment, in-home parent skill-based supports, and kinship navigator services. Getting these services does not affect the child, caregiver or parent's eligibility for any other assistance.
- Seeks to improve licensing standards for relative foster family homes

 The Act seeks to improve state licensing standards for relative foster family
 homes by identifying a Model that states can use to compare and align their standards. It
 also strives to encourage states to use their authority to waive non-safety licensing
 standards for relatives.

• Works to ensure that each child in foster care gets a family

If children need to come into the custody of the child welfare system, the Act encourages the placement of children in foster care in the least restrictive, most family-like settings appropriate to their needs by restricting the use of federal funds for group placements that are inappropriate. The Act aligns with the principle that children do best in families.

• Extends child and family services programs

The Act extends funding for five years for two critical service programs for children and families in the child welfare system-- The Stephanie Tubbs Jones Child Welfare Services Program and The Promoting Safe and Stable Families Program.

- Improves the John H. Chafee Foster Care Independence Program

 The Act extends to age 23 the financial, housing, counseling, employment, education, and other appropriate supports and services to former foster care youth. It further extends eligibility to age 26 for Education and Training Vouchers.
- Reauthorizes the Adoption and Legal Guardianship Incentive Program

 The Act reauthorizes for five years the Adoption and Legal Guardianship

 Incentive Payment program, which allows states to receive incentive payments based on improvements in increasing exits from foster care to adoption or kinship guardianship.

A few of these provisions – not the major section calling for preventative services – were introduced in 2017 in the House of Representatives as smaller, standalone bills. Among those bills is the Reducing Barriers for Relative Foster Parents Act.

Reducing Barriers for Relative Foster Parents Act

In June 2017, the House passed the Reducing Barriers for Relative Foster Parents Act, H.R. 2866, in a landslide victory 382 to 19. The legislation helps address barriers to licensing grandparents and other relatives raising children as foster parents. It requires states to report to the U.S. Department of Health and Human Services (HHS) about their state licensing standards, which are individually created by each state and often cause unnecessary barriers for licensing relatives. States must specifically indicate if their standards are "in accord with HHS-identified model standards", and if not, why not. States must further report if they use federal authority to waive non-safety standards for relative foster family homes, and essentially how that process works. Although the legislation does not directly reference the Model Family Foster Home Licensing Standards that Generations United created in partnership with the American Bar Association Center on Children and the Law, the Annie E. Casey Foundation (AECF) and the National Association for Regulatory Administration (NARA), Rep. Sewell (D-AL) and Rep. King (R-PA) did a colloquy on the House floor that highlighted these Model Standards.

The Model Family Foster Home Licensing Standards are the first set of comprehensive national model standards. NARA, as the nation's association of human service regulators, took the added step of adopting them as its standards (NARA, 2014). This model does away with artificial barriers, such as requirements to own vehicles, be no older than age 65, have high school degrees, and live in homes with certain square footage. In their place are reasonable standards that lead to safe and appropriate homes and families. For example, functional literacy is required, rather than high school diplomas; capacity standards are based on home studies; and other methods of transportation, including public transportation, may be used.

Improve Support for Kinship Caregivers Act

Another piece of legislation, which GrAND Voices have helped influence, is the Improve Support for Kinship Caregivers Act, which Rep. Danny Davis (D-IL) introduced in 2016 (HR 5354). This legislation was not enacted, and Rep. Davis hopes to reintroduce it in 2017. This bill does several critical things to help grandfamilies both inside and outside the foster care system. It calls for important reforms to the Temporary Assistance for Needy Families (TANF) or "welfare" program, which would help grandfamilies. The legislation would exempt caregivers aged 60+ from work requirements, time limits and asset tests, so these caregivers can get on TANF family grants and receive more assistance to help meet the needs of their new family. The legislation would also allow each child on a TANF child-only grant to receive the same amount of financial assistance as all the other children on a TANF child-only grant in the home. Unlike with monthly maintenance assistance payments for children in foster care, the amount each child receives of TANF only goes up incrementally for additional children. In foster care, the amount is the same for any additional foster children in the home. This bill would remedy that disparity.

The bill also calls for several other reforms to help the families, in addition to specifically calling for states to compare and align their foster care licensing standards with the Model Family Foster Home Licensing Standards, created by Generations United, AECF, NARA and the ABA.

Child Welfare Oversight and Accountability Act of 2017

In October 2017, a significant piece of child welfare legislation was unexpectedly introduced in the Senate, the Child Welfare Oversight and Accountability Act of 2017 (S. 1964). This legislation would make several reforms to the child welfare system, including significant changes to the requirements for children to be eligible for the Guardianship Assistance Program (GAP). For a child's GAP eligibility, this legislation provides:

(1) The relative no longer has to be a licensed foster parent. Instead, the relative must pass the criminal and child abuse background checks required by the federal Adam Walsh Child Protection and Safety Act of 2006.

- (2) The child must live in the relative's home for a total of only three months prior to obtaining guardianship assistance, as opposed to now waiting for six months after the relative is licensed to obtain assistance.
- (3) The child no longer has to meet strict income requirements under the outdated Aid to Families with Dependent Children (AFDC) guidelines. Like adoption assistance, GAP would now be delinked from AFDC.

If this legislation is enacted, federal child welfare monies could be used to pay for GAP for many more children exiting the foster care system to live permanently with relative guardians. This would help the many states who use their own limited funds to provide monthly guardianship assistance for non-IV-E eligible children to exit foster care to live with relative guardians. It would also help those children in states that have the federal GAP option, but do not offer a similar program for non-IV-E eligible children.

Federal Court Ruling for "Approved" Kinship Placements – D.O. v. Glisson

In addition to activity on Capitol Hill, an important federal court decision was recently decided -and in effect upheld by the U.S. Supreme Court- that could help many grandfamilies. On October 10, 2017, the U.S. Supreme Court refused to hear an appeal from the Kentucky Cabinet for Health and Family Services seeking to overturn a ruling that the state must pay relatives "approved" to care for children in foster care, just as they do "licensed" foster parents. Because the U.S. Supreme Court refused the appeal, the Sixth Circuit decision is now the law for the states it covers: Kentucky, Ohio, Michigan and Tennessee.

According to the decision, Kentucky must now provide monthly foster care maintenance payments to any relative "approved" by the state to provide foster services for a child in the legal custody of the Cabinet. In Kentucky, approval means that the relative has gone through a home study and a background check, but has not been formally licensed as a foster parent. Kentucky must pay maintenance payments, according to the Court, until the state no longer has legal custody, because the child has been reunified with his/her parents or the child's case is closed through adoption or permanent legal custody.

The decision should also impact Ohio and its similarly "approved" relative caregivers of children in foster care. The other Sixth Circuit states - Michigan and Tennessee - do not engage in a similar approval practice, so grandfamilies in those states will probably not be impacted.

Had the U.S. Supreme Court taken the appeal and upheld the Sixth Circuit decision, it would have impacted grandfamilies around the country. Despite its lack of national applicability, this case is very significant and goes well beyond the U.S.

Supreme Court ruling in *Miller v. Youakim*, which requires that "licensed" relative foster parents receive the same monthly support as "licensed" non-relative foster parents.

Although the U.S. Supreme Court will never hear an appeal of this particular case, it could hear another case in the future with the same core issue. The U.S. Supreme Court likes to hear cases when several of the Circuit Courts do not agree. Although there was one case from the 8th Circuit that had ruled differently than the Sixth Circuit on this issue, the Supreme Court did not take this appeal. Perhaps if there are other cases in the future, and there is a conflict among more Circuits, the U.S. Supreme Court will rule on this issue one day.

The Adoption and Foster Care Automated Reporting System (AFCARS) Final Rule

The third branch of the federal government, the executive branch, has also made policy advances to help grandfamilies. In December 2016, a final rule was published that provides the first update to the Adoption and Foster Care Automated Reporting System (AFCARS) data collection and reporting requirements in over twenty years. It includes numerous changes called for in recent federal law. It also requires for the first-time that states report information related to the Indian Child Welfare Act of 1978 (ICWA).

In 2014 and 2015, Generations United, and numerous other national nonprofits, commented on the proposed changes that eventually became this Final Rule. While commenting, Generations United applauded HHS for many of the proposed changes, which have now become final, to collect:

- longitudinal data on children in out-of-home care, including those with relatives, and detailed penalty provisions if states do not comply
- data on "fictive" kin or individuals with whom "there is a psychological, cultural or emotional relationship between the child or the child's family and the foster parent(s)"
- information on prior adoptions and guardianships that were dissolved or disrupted before entering out-of-home care
- the same data on guardianships as adoptions
- data on guardianships and adoptions even if no financial subsidy is provided on the child's behalf
- information on payment of nonrecurring guardianship and adoption costs
- data on siblings who are living with the child in the adoptive or guardianship home

• data related to American Indian/Alaska Native children and ICWA
All of this data will help states and others better support grandfamilies who raise
children in the foster care system, in addition to the relatives and kin who have adopted
or taken guardianship of children who were previously part of the system.

In addition to supporting the many reforms in the proposed rule, Generations United also suggested a number of changes, including collecting longitudinal data for children receiving adoption and guardianship assistance and data on children diverted from foster care. Although these suggestions and a suggestion concerning successor guardians were not taken, HHS did agree to modify its definition of "kin" so as not to cause confusion among the states. AFCARS already uses the term "relative"; the term "kin" is an addition. "Kin" was used in the proposed rule as solely meaning fictive kin or those with a close or family-like relationship, whereas many states and community organizations define kin as including both fictive kin and those related by blood, marriage, or adoption. HHS agreed to change the definition of "kin" to explicitly exclude relatives by blood, marriage, or adoption, so states can continue to report such individuals as "relatives" and will not get the categories confused or report the same population in two categories.

Although the suggestion asking that data concerning successor guardians be collected was not accepted, HHS did state it its final rule that "We encourage states to consider collecting data that helps states identify how to ensure successors are named in the agreements whenever possible, and to evaluate how to prevent unnecessary re-entry into foster care, but we do not require that they report those data to AFCARS" (Federal Register, 2016).

STATE

States Respond to Grandfamilies and the Opioid Crisis

Like the federal government, many states are concerned about what the opioid crisis is doing to families in general, and grandfamilies specifically. In Ohio, which is one of the states hardest hit by this epidemic, the number of children in foster care placed with relatives has gone up 62 percent since 2010 (PCSAO, 2017). Attorney General Mike DeWine has creatively responded to this crisis by allocating a significant portion of Ohio's federal Victims of Crime Act (VOCA) monies to support families impacted by the crisis in the Appalachian part of the state. Casey Family Programs also made an investment in the program.

Ohio START (Sobriety, Treatment, and Reducing Trauma) will bring together child protective services, peer mentors, the courts, and behavioral health and treatment providers to work closely with families, and provide specialized victim services, such as intensive trauma counseling, to children who have suffered victimization due to parental drug use. The program will also provide drug treatment for parents of children referred to the program. By supporting the children and parents, the relative caregivers who are

raising many of these children, also get much needed assistance.

In June, New Hampshire became the first state in the nation to pass a law, H.B. 629, which gives legal preference to grandparents in guardianship cases involving parental substance abuse or dependence. The law also requires the state department of human services to provide benefit eligibility information on its website and to grandparents applying for guardianship. The bill will go into effect in January 2018.

Washington State repealed Caregiver Means-Testing for TANF child-only

Another advance for grandfamilies came in 2017 when Washington State repealed its 2011 provision calling for means testing of caregiver income for its TANF child-only grants (S.B. 5890). The 2011 policy was contrary to what Congress envisioned and how the majority of states determine eligibility for child-only grants. The overwhelming number of states only test child-income since the grant is only intended for the child and is typically much smaller than a family TANF grant, for which caregiver income is tested.

TANF child-only grants are often the only source of financial support to meet the needs of children in kinship families, and this 2011 policy had some profoundly negative effects on the families. Over 1,500 children were cut off from assistance in the first couple of years after the provision went into effect. This cut was generally due to the fact that caregivers did not want to submit their personal financial information, not because they had too much income (Beltran, 2014). By repealing this provision, Washington has taken a step forward in improving support for grandfamilies. The change is expected to go into effect July 2018.

State Interest in Model Family Foster Home Licensing Standards Growing

For those grandfamilies involved with the child welfare system, states are also making efforts to better support them. Several states have shown interest in removing barriers to licensing relatives as foster parents. These barriers are often caused by their own family foster home licensing standards, so they are looking to the Model Family Foster Home Licensing Standards as a tool for reform. In May 2016, South Carolina passed legislation, SC Act 187, with home capacity language from our Model Standards. Other states that have expressed an interest in the Model include Kansas, Louisiana, Mississippi, Rhode Island, Virginia, Vermont, Washington and West Virginia. In Massachusetts, the Child Welfare League of America (CWLA) used the draft Model standards and the research done to develop those standards when consulting with the state on a critical case and a review of some of its family foster home licensing standards. In its report to Massachusetts, CWLA recommended that Massachusetts consider adopting the Model Standards (CWLA, 2014).

More Jurisdictions Take the Guardianship Assistance Program (GAP) Option

When licensed as foster parents, grandparents and other relatives may be able to exit foster care with their related children into guardianships and receive monthly assistance through the Guardianship Assistance Program (GAP). Thanks to the 2008 Fostering Connections to Success and Increasing Adoptions Act, GAP is an option offered to states and tribes, which for the first time allows them to use federal child welfare monies to finance monthly financial assistance to licensed relative foster parents who become guardians of the children in their care. Since the last policy update in this Journal in 2015, 4 more states -- Minnesota, Nevada, New Mexico, and North Carolina -- and three more tribes -- Eastern Band of Cherokee Indians, Navajo Nation, Pascua Yaqui Tribe -- have taken the GAP option. This brings the total number of jurisdictions with GAP to 35 states, the District of Columbia and eight tribes (Beltran, 2017). This is a great advance for children and youth who wish to exit the foster care system into the permanent care of their loving relative.

Conclusion

With each policy update in this Journal, there have been encouraging reforms to report. Grandfamilies are better supported both inside and outside the foster care system than they were even just five years ago. This is encouraging. Much, however, remains to be done. With GrAND Voices elevated and speaking their truths and experiences to policymakers, it is expected that the next policy update will have even more good news.

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National Research Center on Grandparents Raising Grandchildren

Mission

Our mission is to improve the well-being of grandparent-headed families by promoting best practices in community-based service delivery systems, and to advance the work of practitioners and scholars in the development, implementation and evaluation of new knowledge and services in the field.

Core Beliefs

Grandparents contribute to the preservation of family systems when taking on the responsibility of raising their grandchildren. Grandchildren, as well as all children, deserve to loved and cherished in safe and nurturing families. Parents should have primary responsibility for their children, but when they are unable/unwilling to assume that role, grandparents should be given the resources and support to assist them in managing parental responsibilities. Generally, communities are better served by grandparents taking on the custodial care of their grandchildren, when needed.

Center Goals

- Influence new scholarship that merges the fields of aging, child welfare, and family research in the context of intergenerational caregiving.
- Communicate and disseminate evidence-based research and practice strategies to practitioners, researchers, policy advocates, and grandparent caregivers.
- Promote training and professional development of service practitioners and other allied professionals working with grandparent caregivers.
- Endorse the replication of evidence-based strategies to support better outcomes for children, families, and communities across the nation.
- Support current and emerging researchers and practitioners working in the fields aging, child welfare, and family services to sustain efforts leading toward positive social change for intergenerational families.