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CUSTODIAL GRANDMOTHERS RAISING CHILDREN WITH DISABILITIES AND THE STRESSORS THEY FACE

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CUSTODIAL GRANDMOTHERS RAISING CHILDREN WITH
DISABILITIES AND THE STRESSORS THEY FACE

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Kanika Oni Kisero

June 2015

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ABSTRACT

Stressors that custodial grandmothers face while raising children with disabilities can be more overwhelming compared to stressors experienced by grandmothers of non-disabled children. Strategies and various supports were looked into in order to determine how custodial grandmothers practice self-care so they may experience positive mental health outcomes. A purposive sample of custodial grandmothers was surveyed and the results obtained provided some support on how self-care is and is not practiced in order to manage stress. This study resulted in non-significant findings, which did not support the hypotheses. Additional analysis was used to gauge levels of stress, but could not provide evidence to support the hypotheses. Overall, understanding the challenges custodial grandmothers face while raising disabled children has provided insight to the occurring stressors, practicing of self-care to aid in promotion of positive mental health outcomes, and the need for further research to address this population of people.

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Thank you to all the participants in my study. The work you to do to ensure kin children remain within their birth family is admirable. Also thank you to Vanessa Beckles for your patience and support.

DEDICATION

I thank God for guiding me through this program. Self-doubt, fear of having to quit and being able to manage school, work and personal life all at once, is all by His grace.

To my husband for your love, support, and encouragement. The demands of this program made us miss some time together and vacations were either shortened or non-existent; so I am very grateful for your patience and understanding. I thank you and I love you so much.

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CHAPTER ONE

INTRODUCTION

Problem Statement

In the 2010 U.S. Census data, 2.7 million children were living with a grandparent seen as their primary caregiver; 1.7 million of those children were under the age of 18 and living with their grandmothers (“2010 Census Data - 2010 Census,” n.d.). Since U.S. Census data cannot record all grandparents in a population, utilizing other research [secondary analysis shows that almost 11 percent of grandparents had primary responsibility for raising a grandchild for six months or more, with most caring for a grandchild for much longer periods (Grinnell & Unrau, 2011). This has been a determining factor in what constitutes as a custodial grandparent (Lumpkin, 2008).

In particular, studying custodial grandmothers raising children with disabilities; the hope is to substantiate the importance of practicing self-care so that stress levels can be managed. Self-care is defined in two parts as belonging to oneself and ensuring something is safe, healthy or in good condition (Merriam-Webster's online dictionary, n.d.).

A sub-set interest also lies in caregivers of children with developmental disabilities. Researchers have found elevated levels of psychological distress in grandparents raising developmentally disabled grandchildren (Kelley, Whitley, & Campos, 2010). Custodial grandparents of grandchildren with developmental disabilities are a sub-culture that has been under-researched

(Mitchell, 2006). Some tasks when maintaining a developmentally disabled child's care can require administering of medications and may require additional training and support for the caregiver (Mitchell, 2006). Stressors that are linked to the care-giving placed on a grandparent puts them at risk for the development of health problems, anxiety and depression being the frequent mental health concerns (Leder, Nichol森-Grinstead, & Torres, 2007).

Additional caring responsibilities and emotional demands are frequently faced when raising children with disabilities (Mitchell, 2006). The demands on their finances, their need to advocate on behalf of the disabled grandchild and often a reduction in socialization with other adults, exacerbate stressors on the grandparent (Hillman, 2007). Task difficulty, time involved in tasks, difficult child behavior and the level of child's disability also are stressors on the caregiver (Plant & Sanders, 2007). Developmental disabilities are categorized as being a physical or mental disability (such as mental retardation) that becomes apparent in childhood and prevents, impedes, or limits normal development including the ability to learn or to care for oneself (Merriam-Webster's online dictionary, n.d.).

Developmental disabilities can include Intellectual Disability (formally mental retardation), Cerebral Palsy, Autism Spectrum Disorder, and Epilepsy (Hillman, 2007). "One in 166 grandparents will become a grandparent to a child with Autism Spectrum Disorder" (Hillman, 2007, p. 513). Children with developmental disabilities are often dependent on parents to meet their needs

therefore care-giving tasks are more burden-some, and as a consequence the parent experiences higher levels of stress (Musil, Warner, Zauszniewski, Wykle, & Standing, 2009). Reviewing available studies, certain disabilities like autism are often reported by grandparents as causing higher stress levels than disabilities like intellectual disabilities or cerebral palsy as reported by other grandparents, due to the behavioral issues that are characteristic of most autistic children (Hillman, 2007).

Policy Context

Once a grandparent takes on a custodial role, similar experiences of stress apply just as in the cases for parents or other caregivers; therefore education and policy need to be in place to help grandparent(s) redefine their role, share in the diagnosis and treatments for a disabled grandchild, and obtain social support (Hillman, 2007, p. 513). For custodial grandparents, substantiated findings on stress and rates of depression can adversely affect the overall health for those with preexisting health conditions (Musil et al., 2009).

Areas of support that are beneficial to custodial grandparents are joining local support groups for care-givers of children with developmental disabilities, utilizing respite care (if available), being educated on how to better serve a grandchild with developmental disabilities and obtaining behavior modification services to help alleviate stress in the care of their grandchild (Hillman, 2007). Promotion of policies that can provide appropriate and

properly staffed daycare and after-school care would provide dual benefits (Hillman, 2007). Linking grandparents to agencies that provide comprehensive services is another way to support them. Continuing educational programs for professionals including psychologists, social workers, counselors, behavioral specialist, clergy, educators, administrators and the general public will assist grandparents (Hillman, 2007). Continuously educating professionals will expand their knowledge and treatment efforts with grandparents.

Purpose of the Study

Research has been conducted on the challenges parents, whether biological or adoptive, face when raising a child or children with disabilities a various forms. Evaluating the role custodial grandmother's play while raising children with developmental disabilities, this is very important to address due to the demands of grandparents taking on a parenting role (Mitchell, 2006).

With people now living longer than before, the average life expectancy is 78.1 years (Hooyman & Kiyak, 2011). These recent trends in a longer lifespan mean that more people are likely to become grandparents (Hillman, 2007). According to Hooyman and Kiyak, most custodial grandparents are under the age of 65, with 20 percent who are age 65 and older (Hooyman & Kiyak, 2011). The role of grandparents within a household become more challenging as more needs of the child have to be met. When a grandparent feels overwhelmed by the stress associated with caring for their child with a

disability, there can be negative implications for the child and the family as a whole (Plant & Sanders, 2007).

Grandparents have to take on the responsibility of the custodial primary caregiver when a parent is absent for reasons such as incarceration, abuse/neglect, military deployment, death, substance abuse, economic issues or parents having a disability themselves (Leder, Nicholson-Grinstead, & Torres, 2007). Not all grandparents welcome this commitment and loss of personal freedom (Mitchell, 2006). The well-being of the grandparents depends on their ability to cope with that stress (Lumpkin, 2008). Therefore the hypotheses are:

Hypothesis 1: Grandmothers who have a support system in place will practice self-care.

Hypothesis 2: Grandmothers who practice self-care will have lower levels of stress.

Social service agencies providing supports and counseling can help grandparents address stressful events in their lives and these hypotheses can be tested within that context.

The Agency

The agency used for the study was Helping Hands Kinship Support Services as part of Mental Health Services of Victorville, California. This agency provides supports and counseling for birth families who are parenting

kin children so that family units maintain stable (“Mental Health Systems”, n.d.).

Significance of the Project for Social Work

This study will provide insight into the unmet needs custodial grandmothers face when taking on the care of children with disabilities. This study has the potential to bring more awareness to medical professionals, social workers, and members within an individual’s family, that when social supports are planned, created and made accessible, custodial grandmothers can be impacted in a positive manner.

CHAPTER TWO

LITERATURE REVIEW

Introduction

Chapter Two presents an overview of the literature reviewed on custodial grandparents raising grandchildren with various disabilities including developmental disabilities. The literature also provides insight to the stressors these grandparents face when taking on that custodial role, self-care practices and policies to be implemented to ensure that grandparents have the opportunity to practice self-care in order to lower their stress.

Prevalence

Research shows that a majority of grandparents raising their grandchildren are women, often single, and come from a lower socioeconomic status (Musil et al., 2009). For those that are not single, the grandmother still is the typical provider for a majority of the care their grandchild requires (Musil et al., 2009). Using national samples, researchers find that custodial grandparenting cuts across gender, class, and ethnic lines; however rates are higher for women and higher among African American and Hispanic groups when compared to Whites (Lumpkin, 2008).

Theories Guiding Conceptualization

Role theory examines most of everyday actions to be defined by social categories (e.g., grandmother, teacher, and mother) (Biddle, 1986). Each *role*

that a person takes on has a set of expectations, norms, duties, and behaviors that are expected to be fulfilled (Biddle, 1986). Another important concept of role theory is that, “human beings behave in ways that are different and predictable depending on their social identities and the situation” (Biddle, 1986, p. 68). A role can be defined as a social position, behavior associated with a social position, or a typical behavior (Biddle, 1986).

Two differences within role theory pertain to functional perspective approach and symbolic interactionist approach (Biddle, 1986). The functional perspective looks at who occupies social positions within a stable society; the “actor” of the role has presumably been taught there norms and may be expected to conform to norms for their own conduct (Biddle, 1986). The symbolic interactionist approach allows for roles to evolve through social interactions and various cognitive concepts through which the “actor” of the role understands and interprets their own and other’s conduct (Biddle, 1986). Another aspect to this theory is that *role conflict* occurs when a person is expected to simultaneously act out multiple roles that carry contradictory expectations (e.g., a grandmother now becoming a mother again) (Biddle, 1986).

Role theory’s approaches can be conceptualized as, “a triad of patterned and characteristic social behaviors, parts or identities that are assumed by social participants, and scripts or expectations for behavior that are understood by all and adhered to by performers” (Biddle, 1986, p. 68).

How Problems Are Defined by Theory

Theories can help conceptualize why problems occur. If a researcher can conceptualize a problem, then they have a foundation to generate questions and collect tools necessary to begin work on those problems. Whether a problem is or is not fixed, it is presumed that theories can still guide a researcher on what works or give insight to why something does not work.

Looking at the symbolic and functional perspectives within role theory, people are either taught to act a particular way or they continuously evolve based on society's standards (Biddle, 1986). When a person has to conform to a set role, they may have difficulty accepting that change and may become resentful for what they feel they will lose if that change occurs (Mitchell, 2006). By using theory, researchers gain perspective through trial and error, which allows forward progress by providing answers to the questions being asked.

How Solutions Can Be Informed by the Theory

By analyzing theories on how roles are constructed and played, solutions to problem areas can be formulated. Educating grandparents of children with developmental disabilities is very important because if they can accept their new role as the primary care-giver as well as gain knowledge on how to best support their grandchildren, their anxiety will be less heightened (Leder, Nichol森-Grinstead, & Torres, 2007). Professionals can assist in educating and empowering, putting in place services like daycare/respite care

or behavior interventions in order to give the grandparent “free time” to themselves (Joslin, 2009).

Within that “free time” there is an assumption that grandparents may meet with friends, attend support groups, exercise, and complete errands, attend their own medical appointments, sleep, or participate in a hobby. Conducting the study will confirm if any, all, or additional strategies are used to lower stress levels. This process of finding what works, what does not, how to apply it, when to apply it, how to produce resources and when to distribute those resources are how theories guide people to generating solutions.

This study looks into two main factors in regards to the role custodial grandmothers of children with disabilities and the stressor they face:

- 1) What strategies or supports need to be in place in order for custodial grandmothers of children with disabilities to practice self-care?
- 2) Can stress be lowered when self-care is practiced?

With these questions the intention is to show grandmothers ways to practice self-care and for those who may be practicing some form of self-care, to expand on ways of doing it so that a positive mental health status can be maintained.

Additional Findings

Research has shown that some custodial grandparents of grandchildren with developmental disabilities go through a period of mourning; grieving for the loss of the grandchild and relationship they expected to have

and the need of accepting a new role (Hillman, 2007). Plant and Sanders (2007) stated that “Stress is influenced by the coping processes of cognitive appraisal, coping strategies and coping resources” (p. 110-111), an individual may have. Additional findings reported by Musil et al., 2009 found that:

Subjective support moderated the effects of strain and instrumental support moderated the effects of family life stresses on depressive symptoms. Social support and resourcefulness may help protect grandmothers from the effects of family stresses and strain, and interventions to enhance these factors may assist grandmother caregivers to achieve better mental health. (p. 389)

Due to the challenges of being a caregiver, research findings provide support on why resources of many varieties need to be accessible to best support grandparent caregivers.

Summary

This chapter provided a review of literature that relates to grandparents as caregivers to children, emphasizing children with developmental disabilities. In review, role theory was also conceptualized to show how easily an individual or specific population of people gain and lose “roles” as other factors contribute to the development of the new role.

CHAPTER THREE

METHODS

Introduction

This chapter gives an overview of the methods used to study the self-care practices of custodial grandmothers raising children with physical and developmental disabilities. Details of how data was retrieved, methods utilized, sampled population and instruments used are incorporated to show how this study was completed.

Study Design

With prior research on the self-care practices of custodial grandmothers raising children with disabilities being limited, the goal for this study was to obtain results that give light to the experiences of grandmothers raising these children.

Women ages 40 and older who are the custodial grandparents of a child with a disability by means of guardianship or adoptions were sought to participate in this research study. The study was open to all ethnic groups of all socioeconomic backgrounds with a sample of 22 participants (N = 22). This study allowed custodial grandmothers to convey the potential stressors endured when having to parent a child with a disability. The hypotheses are assessing the levels of stress these grandmothers are facing and supportive

ways to improve how these grandmothers can practice self-care will be explained.

Sampling

A purposive sample of custodial grandmothers was sought and asked to complete a survey that measures their stress in being a caregiver of a child with a disability. A purposive sample is a deliberate non-random method of sampling a group of people with a particular characteristic (Margetts, LeCouteur, & Croom, 2006, p. 567). The sample consisted of 22 participants who returned the survey. Participants were recruited from Helping Hands Kinship Support Services a program overseen by Mental Health Systems located in Victorville, California.

Sample Population

The sample is comprised of twenty-two female caregivers raising at least one child with one or more disabilities. Gender was solely female as this was a purposive sample to study custodial grandmothers raising children with disabilities and the stressors they face.

Independent and Dependent Variables

The independent variables are: age (participants were asked to list last birthday). Ethnicity was re-coded as Black/African American (one) and, White/Caucasian (two). Other group was re-coded as zero to include Hispanic/Latino, Bi or Multi racial and Asian as these ethnic groups had the lowest number of participants.

Level of education was coded as one less than high school, two coded as high school graduate, three coded as some college, four coded as college graduate and five coded as graduate or professional school. Socioeconomic status was based on sources of income with employment coded as one, Social Security Income (SSI) was coded as two, pension/retirement was coded as three, and TANF (government assistance) was coded as four. Annual income ranged from less than \$9,999 to \$50,000 or higher. Marital status was coded one, never married, coded as two married, coded as three divorced, four coded as widowed and five coded as other. These variables were not used in the analysis as no significant relationships were found; however they are relevant to demographics.

The dependent variables are: stress and self-care activities. These two variables are what were tested.

Data Collection and Instruments

The levels of measurement were nominal and scale. The survey as, shown in Appendix A, titled Assessment of the Needs of Caregivers (ANOC), (J. Chang, personal communication, March 12, 2014), was a paper and pencil survey used for this study. This scale allows participants to rate their role as caregivers and levels of stress/strain encountered, while managing the care of their child with a disability. The nominal and scale questions ranked the caregiver's level of agreement to stress they may endure, while raising their child. Questions required a response of either yes or no (1 = yes, 2 = no) and

other questions were rated on a 5 point scale, if participants felt very good (5), good (4), fair (3), poor (2) and very poor (1) about factors causing potential stress.

The strength of the data collection methods is that participants were in one central location. The limitations were that questions in the survey may not have pertained to some participants, especially those whose culture or religion changes their view on the role or expectations of a caregiver. Also, the research excluded other kin caregivers such as grandfathers, extended relatives, and/or siblings.

Procedures

Custodial grandmothers currently attending Helping Hands Kinship Support Services as part of Mental Health Systems were sought for this study. Participants took the survey from June 2014 through January 2015. Participants completing the surveys received gift certificates in the amount of two-dollars to Baskin Robbins® ice cream store as an incentive for their participation. Participants were given contact information via letters, as shown in the appendices, of the research coordinator and supervisor of this research study at California State University, San Bernardino if they had questions or concerns. They also received notification by word-of-mouth from onsite staff regarding a study taking place at the agency.

Protection of Human Subjects

In order for this study to be conducted efficiently and anonymously, surveys were asked to be returned to the onsite locked return box at Mental Health Systems in Victorville, California. Participants did not have to be personally interviewed. Informed consents, confidentiality shown in Appendix B and debriefing statements, shown in Appendix C were given to participants, upholding their confidentiality and anonymity. Permission to conduct research at Mental Health Systems was received via letter as shown in Appendix D. Also, to protect anonymity, flyers, as shown in Appendix E, were placed inside the main office to notify grandmothers of research being conducted.

Data Analysis

This study took a quantitative approach to collecting data. The Assessment of the Needs of Caregivers (ANOC) used for this study measured the caregiver's stress/strains. A correlation matrix was completed to see what variables should be analyzed. All scores were analyzed using bivariate level of analysis. Further analysis of the data was conducted by running a correlation matrix to determine variable significance. By obtaining variable significance, cross-tabulations between variables provided details as to which variables correlate best. When analyzing the association between nominal variables Chi-Square and ANOVA were used. The Independent sample t-test analyzed comparable means.

Summary

Chapter Three breaks down the methods for this study by providing detailed information to the study design, the sampling, the collection of data and instruments used, procedures, protection of human subjects and data analysis.

CHAPTER FOUR

RESULTS

Introduction

Chapter Four provides an explanation of the data that were collected and what tests were run to interpret the data in order to explain what the results mean for this study. An analysis of the data determined if the hypotheses were supported in measuring caregiver stress for custodial grandmothers raising children with disabilities.

Presentation of the Findings

Due to small sample size ($N = 22$) an attempt to perform analysis provided the following results.

Demographics

Gender, all respondents were female. Age, the respondent's ages ranged from forty to eighty-one with $M = 57.45$, $SD = 7.90$. Ethnicity, one respondent (4.5%) self-identified as Asian, eight (36.4%) self-identified as African American, seven (31.8%) self-identified as Caucasian, three (13.6%) were self-identified as Latino, two (9.1%) self-identified as multi/bi-racial, and one (4.5%) self-identified as other (Iranian). Level of education, categorical options were: less than high school, high school graduate, some college, or graduate/professional school. Two respondents (9.1%) had an education less than high school, eight respondents (36.4%) were high school graduates, nine respondents (40.9%) had some college, and three respondents (13.6%) were

graduates of college/professional school. Sources of income, respondents had the option to select one or more of the following: employment, Social Security Income (SSI), pension/retirement, or Temporary Assistance for Needy Families (TANF/welfare). Ten respondents (45.5%) selected employment, thirteen respondents (59.1%) received social security due to their child's disability, five respondents (22.7%) received pension/retirement and four respondents (18.2%) received TANF/welfare.

Current annual income, three respondents (13.6%) reported making less than \$9,999, six respondents (27.3%) made between \$10,000 and \$19,000, two respondents (9.1%) made between \$30,000 and \$39,000, four respondents (18.2%) made between \$40,000 and \$49,000 and seven respondents (31.8%) made \$50,000 or more. Marital status options: never married (13.6%, three respondents), married (50%, 11 respondents), divorced (22.7%, five respondents), or widowed (13.6%, three respondents).

Frequencies

How would you rate your current stress level while managing your child's care? They had the option to select none (no stress), mild stress, moderate stress, or severe. One respondent (4.5%) selected none, six respondents (27.3%) felt their stress was mild, eleven respondents (50.0%) said they have moderate stress and four respondents (18.2%) felt their stress being a caregiver was severe.

Do you currently seek support from others (i.e., family, social workers, religious supports, and your community)? Nineteen grandmothers (86.4%) reported yes and three (13.6%) reported no.

If applicable, does spirituality, faith, or religion help reduce your stress? Seventeen grandmothers (77.3%) reported yes, three (27.3%) reported no and two (9.1%) did not answer.

Do activities such as exercising, reading, cooking or more help relieve stress while raising your child? Sixteen grandmothers (72.7%) reported yes that one of these activities helps reduce their stress, while six grandmothers (27.3%) reported no.

Do you currently take time for yourself to prevent becoming overwhelmed while raising your child? Twelve grandmothers (54.5%) responded yes and ten (45.5%) responded no.

A correlation matrix was completed to see what variables should be analyzed. All scores were analyzed using bivariate level of analysis.

Chi-square

Hypothesis 1: Asks what strategies or supports need to be in place in order for custodial grandmothers of children with disabilities to practice self-care? There was no significant association between currently seeking help from others and ethnicity $\chi^2 = 1.631$, $df = 5$, $p = .90$. Hypothesis 2: Asks can stress be lowered when self-care is practiced? There was no significant association between currently seeking help from others and does spirituality,

faith or religion help reduce your stress $\chi^2 = 1.022$, $df = 2$, $p = .60$. There was also no significance between do activities such as exercising, reading, cooking etc, help relieve stress, while raising your child and do you currently take time for yourself to prevent becoming overwhelmed, while raising your child $\chi^2 = .070$, $df = 1$, $p = .80$.

Additional analysis was performed, not to provide evidence to support the hypotheses; however, to gauge levels of stress. There was a significant association between, has caring for your child with a disability caused you to feel sad or depressed and has caring for your child with a disability been physically demanding $\chi^2 = 6.90$, $df = 1$, $p < .05$. This correlation assisted in gauging levels of stress as feelings of sadness or depression compounded with the physical demands of raising a child with disabilities added to caregiver stress. It was not used to provide evidence to support Hypothesis 1.

ANOVA/Post Hoc

Hypothesis 1: What strategies or supports need to be in place in order for custodial grandmothers of children with disabilities to practice self-care? There was no significance between marital status and how would you rate your current stress, while managing your child's care, $F = .134$, $df = 3$, $p = .94$; therefore it does not support Hypothesis 1.

T-Test

There is significant association between caregiver's current stress and raising a child with disabilities as being an inconvenience. The independent

sample t-test found a significant difference in the means between these variables. The groups mean score for respondents who rated current stress and inconvenience being a caregiver was 3.0667. Those who did not see caregiving as an inconvenience was 2.2857. This difference was significant ($t = 2.370$, $df = 20$, $p = .028$).

The relationship between has caring for your child with a disability been an inconvenience to you and do you currently take time for yourself to prevent becoming overwhelmed, while raising your child was also significant. The group score of those reported yes ($n = 12$) was 1.5833 and for those reporting no ($n = 10$) the mean score was 1.0000. This difference was significant ($t = 3.568$, $df = 20$, $p = .002$). The caregiver's current stress and feeling overwhelmed was significantly associated. Caregivers that reported being stressed were overwhelmed with their responsibilities as a caregiver.

Summary

Chapter Four detailed results gained from the project. A majority of non-significant associations were found between the measurements. Significant findings that were found showed there is a correlation between the stress custodial grandmothers face while raising children with disabilities.

CHAPTER FIVE

DISCUSSION

Introduction

Chapter Five brings a conclusion to this project. Further descriptions of this study will be covered. Study limitations and recommendations for further research will also be mentioned as well as a summarization of the implications for social work practice.

Discussion

This was a purposive sample specifically seeking grandmothers. A majority of respondents were African Americans (36.4%). This study helped gauge the level of stress grandmother are currently facing while raising their child with a disability, as well as other factors that compound their stress. Some of those factors included lack of service connection and the physical demands of caring for children with disabilities.

A majority of caregiver respondents reported that faith/spirituality or doing activities such as cooking, exercising, or reading was supportive in reducing their stress. A majority of caregiver respondents were also married and reported utilizing family support to assist them. It became apparent that caregiver stress may not be reduced even with these supports in place as a majority of reports on current stress were rated as moderate across all ethnicities.

It became recognizable when asked do you currently take time for yourself to prevent becoming overwhelmed while raising your child, respondents were nearly split; twelve saying “yes” and ten saying “no”. It is possible utilizing family and/or community support as well as participating in self-care activities is beneficial; however examination of the extent and duration those supports play on a daily basis leaves room for further research.

There was no significant association between currently seeking help from others and ethnicity. This result suggests that despite those who do or do not seek help from others has nothing to do with which ethnic background they identify with. There was no significant association between currently seeking help from others and does spirituality, faith or religion help reduce your stress. This result suggests that there can be a variety of ways of seeking support and attempting to lower stress is not determined based on how spiritual/religious a person is or is not.

No significance was found between, do activities such as exercising, reading, cooking etc, help relieve stress while raising your child and do you currently take time for yourself to prevent becoming overwhelmed while raising your child. This outcome suggests that those who do take time for themselves to prevent becoming overwhelmed can do so by means extended beyond activities such as exercising, reading or cooking.

Gauging the stress levels between marital status and how you would rate your current stress level, while managing your child’s care resulted in

there being no significance between the two variables. This result suggests that whether a respondent was never married or married, never married or divorced or never married or widowed had no factor in stress levels being lower or higher while raising a child with disabilities.

Additional analysis that did produce significant relationships was incorporated to gauge stress levels without implying evidence to support either hypothesis. When respondents were asked, has caring for your child with a disability caused you to feel sad or depressed and has caring for your child with a disability been physically demanding, this result was significant. The result suggested the probability that feelings of sadness or depression when compounded with the physical demands of raising a child with disabilities, may contribute to stress caregivers endure.

There was a significant difference in caregiver's current stress and raising a child with disabilities as being an inconvenience (e.g. loss of free time, loss of friendships, isolation from other family members, or the time involved in order to care for your child). Significance was found in the means between these variables, which results asserted that respondents experiencing stress while raising a child with disabilities are likely to experience disruptions within personal life routines due to the inconvenience of being a caregiver.

When addressing the relationship between has caring for your child with a disability been an inconvenience to you and do you currently take time

for yourself to prevent becoming overwhelmed while raising your child; also resulted with significant findings. It can be asserted that caregivers who saw their caregiver role as inconvenient felt overwhelmed by their stress raising their child. In an effort to bring some support to the study conducted similar conducted studies have found results within this population.

A study of grandparent caregivers conducted by Force, et al., (2000) found the following:

Grandparent caregivers of grandchildren with developmental disabilities showed high rates of depression, but not significantly higher than that of other grandparent caregivers. In their study of 164 grandparents caring for a child with developmental disabilities in New York, of which nearly all were female (96%) and African-American (80%), report that most of these families felt overwhelmed by the caregiving challenges. (Force et al., as cited in Heller & Ganguly, n.d., p. 12-13)

For this research there is a possibility that if a larger sample of participants over larger geographical areas were to be obtained, more data could have been obtained potentially giving relatable analyzed results. The literature review has shown through research evidence that grandmothers are affected by stress as their responsibilities of being a caregiver to a child and/or children with disabilities are required.

Limitations

Working with a small sample (N = 22) limited the ability to analyze data across multiple tests. Variables that computed significant values within the correlation matrix often did not benefit answering the hypotheses. It is possible that adaptations to the survey in order for stress and self-care/supports to be referenced more, would have been beneficial as those variables were the main references to either accept or reject the hypotheses. By not including the word “stress” or including more questions relating to self-care/supports, most survey questions may have appeared biased as assuming various factors caused stress in the participant’s lives.

This study would have also been more beneficial if qualitative self-reports were obtained in order to gain more perspective on caregiver stress and needed resources. Other programs outside of Helping Hands Kinship Services could have been researched or referred to for these grandmothers. Question 11 of the survey gave the option for a written response; however additional comments were not received regarding service agencies or programs that may be in use. This leads to the belief that these participants were either not aware of other agencies, for example, Inland Regional Center. If they were aware of this resource, it is probable that they may have not taken their child and/or had qualifiable criteria for Inland Regional Center services. Participants also may have opted not to list what services they receive.

Another potential limitation was the use of incentives such as Baskin Robbins gift certificates. This incentive may have solicited participants who may not have been appropriate to participate in this study. Helping Hands Kinship Services serves various kinship caregivers; not solely grandmothers who are caregivers. There was also the possibility that participants may have answered questions unfairly just to receive the incentive.

It is important to note that more recent studies have shown that many families also experience positive outcomes through parenting children with disabilities. Such outcomes include, “increased tolerance and understanding of disability conditions; increasing patience, compassion, and altruism; strengthening of family relationships and cohesion, positive relationships with school and community members professionals” (Lee & Gardner, 2010, p. 468).

Participants from the study on Custodial Grandmothers Raising Children with Disabilities and the Stressors They Face, who reported they endured stress or saw being a caregiver as inconvenient, were part of a small sample. The smaller sample size does not diminish the fact that research on stressors for grandmothers who are raising children with disabilities could be expanded on in future research. Bringing these concerns to a wider audience in order for policy and service consideration to be implemented, could benefit an oppressed population (Mitchell, 2006).

Recommendations for Social Work Practice, Policy and Research

Social Work Practice

Most grandmothers who participated in this study reported being the caregiver to a child with a diagnosis of Autism and/or Intellectual Disabilities. Developmental disabilities such as these can often be evaluated through the Inland Regional Center when medical professionals refer, by self-referral, or by social workers (“Inland Regional Center”, n.d.). Social work practice requires knowledge of various community resources and networking to ensure consumers or services are supported in the best ways possible.

Agency collaboration/networking would benefit these grandmothers as one agency may have more to offer than another. County social workers and adoption workers should also provide information regarding disabilities and offer parenting classes throughout the adoption process in order for these grandmothers to be best educated as the child is placed in their care.

Policy and Research

Even though policy changes have caused an increase in how many grandparents, who are caregivers, becoming eligible for kinship-care payments, many are still unsuccessful when trying to receive the support needed when seeking resources (Roe & Minkler, 1996). According to Force, Botsford, Pisano and Holbert (2000) it is stated that “Social policy has not kept up with demographic changes such as increased longevity, diversified families, and changes in women’s roles both as single parents and as

grandparents” therefore multiple challenges exist (p. 5). The concerns within the grandparent caregiver population remain current due to advances in medical care which has reduced pre and post-natal mortality rates of children, including those born with disabilities (Force, Botsford, Pisano, & Holbert, 2000).

Services like support groups have offered vital short-term emotional support, informational support, and tangible support to grandparent who encounter hardships of raising children (Roe & Minkler, 1996). Some smaller support groups join together and briefly meet while others continue to meet over years (Roe & Minkler, 1996).

A variety of resources need accessing and according to Roe and Minkler (1996) “One of the most important potential supports for system and policy advocacy, as well as for local program development, is the resource center. Resource centers serve as clearinghouses for grandparents and professionals in need of assistance or referrals” (p. 6); therefore the benefit can apply to so many. When looking at larger resource centers, more services like integrated resources assist not only the individuals, but all those in social services who also utilize them for conferences, community meetings, forums on current policy issues, as well as client advocacy (Roe & Minkler, 1996).

Conclusions

The utilization of programs and program development can tackle many stressors grandmothers currently face or potentially may face. It is also

apparent that any lack in resource, whether within the home or community, contributes to the stress grandmothers have self-reported. For programs and services that are readily available, grandmothers also have to be willing to accept available services. Participants from this research conducted at Helping Hands Kinship Service, are utilizing the support groups services; however, it is not well known if additional services offered by this service agency, such as mentoring, basic care needs, respite care, advocacy, caregiver workshops, transportation assistance and case management are being utilized.

There is hope that this research brings more awareness to the factors that cause stress in the lives of custodial grandmothers raising children with disabilities in order for overall well-being is managed.

APPENDIX A
SURVEY

Assessment of the Needs of Caregivers

You will be asked a series of questions about your knowledge and experience as a caregiver to a child with a disability. If you have more than one child with a disability currently in your care please select only one to answer this survey There are no right or wrong answers and your responses remain anonymous. Please answer honestly as your participation is greatly appreciated.

1. How would you rate your current stress level while managing your child's care?
None _____ Mild_____ Moderate_____ Severe_____

2. How long has your child been in your care?
0-12 months_____
1-5 years_____
5-10 years_____
More than 10 years_____

3. How did you become their caregiver? (Please select one)
Guardianship_____
Adoption_____
Foster care_____
Military deployment of child's parent(s) _____
Death of child's parent(s) _____
Abandonment by child's parent(s) _____
Incarceration of child's parent(s) _____

4. What is your child's disability? (Please check all that apply)
autism_____
epilepsy_____
Cerebral palsy_____
Intellectual disability/mental retardation_____
ADHD_____
Other (specify)_____

5. Does your child require frequent care from doctors, behavioral interventionist, and/or other specialists?
Yes_____
No_____
Sometimes_____

In this section your answers will require you to mark 1(one) for YES or 2 (two) for NO

6. Has caring for your child with a disability caused you to feel sad or depressed?
1=Yes_____ 2=No_____
7. Has caring for your child with a disability been physically demanding on you?
1=Yes_____ 2=No_____
8. Has caring for your child with a disability been an inconvenience to you? (Examples: loss of free time for yourself, loss of friendships, isolation from other family members, or the time involved in order to care for the child)
1=Yes_____ 2=No_____
9. Does your child have any emotional or behavioral problems?
1=Yes_____
2=No_____
10. Is your child medically fragile? (Example: takes multiple medications, requires total assistance, in and out of hospital., has other medical diagnosis)
1=Yes_____
2=No____
11. Do you currently seek help from others? (Examples: family, social workers, religious supports, your community)
1=Yes_____ If so, from who or what source_____
2=No_____
12. How would you rate your child's current health status? (mark either 1-5)
(5) Very good_____
(4) Good_____
(3) Fair_____
(2) Poor_____
(1) Very poor_____
13. How would you rate your current health status? (mark either 1-5)
(5) Very good_____
(4) Good_____
(3) Fair_____
(2) Poor_____
(1) Very poor_____

14. Are you the caregiver for multiple people within your home?
 1=Yes_____ 2=No_____
15. How would you rate your overall satisfaction with being a caregiver?
 (Mark 1-5)
 (5) Very satisfied_____
 (4) Satisfied_____
 (3) Don't know_____
 (2) Somewhat satisfied_____
 (1) Not satisfied_____
16. If applicable, does spirituality, faith or religion help reduce your stress?
 1=Yes_____ 2=No_____
17. Do activities such as exercising, reading, cooking etc. help relieve stress while raising your child?
 1=Yes_____ 2=No_____
18. Do you currently take time for yourself to prevent becoming overwhelmed while raising your child?
 1=Yes_____ 2=No_____

Caregiver Demographics

19. Gender:
 1. Male
 2. Female
20. Age at your last birthday_____
21. Ethnicity:
 Asian American_____
 Black/African American_____
 White/Caucasian_____
 Hispanic/Latino_____
 Bi or multi racial (specify) _____
 Other (specify) _____
22. Level of education
 _____Less than high school
 _____High school graduate
 _____Some college
 _____College graduate
 _____Graduate or professional school

23. Sources of income (check all that apply)

- employment
- SSI (Social Security Income)
- Pension/retirement
- TANF (governmental assistance)

24. What is your current annual income? (Please circle one)

- 1. Less than \$9,999
- 2. \$10,000-\$19,000
- 3. \$20,000-\$29,999
- 4. \$30,000-\$39,000
- 5. \$40,000-\$49,000
- 6. \$50,000 or higher

25. What is your current marital status? (Please circle one)

- 1. Never married
- 2. Married
- 3. Divorced
- 4. Widowed
- 5. Other (specify) _____

APPENDIX B
INFORMED CONSENT

INFORMED CONSENT

PURPOSE: For the study in which you are being asked to participate, research is being conducted to assess the stress/strain on custodial grandmothers raising children with developmental disabilities. This study is being conducted by Kanika Kisero under the supervision of Dr. Rosemary McCaslin, Professor of Social Work. The Institutional Review Board's Sub-committee for the School of Social Work at California State University, San Bernardino, has approved this study.

DESCRIPTION: In this study you will be asked a sequence of questions about your child's disability, your age, source of income, overall well-being, marital status, level of education and your ethnicity.

PARTICIPATION: Your participation in this study is completely voluntary. You may leave the study at any time and you have the option to not answer a question.

ANONYMOUS: Your identity will remain anonymous. All of the information collected will be used to conduct research and will properly be discarded once the study is complete.

DURATION: For completion of this survey it is estimated that you will need 15-20 minutes to complete it in its entirety.

RISKS: If for any reason taking this survey causes minor distress, information regarding crisis and counseling hotlines are included in the debriefing statement you will receive.

BENEFITS: Participants will receive a gift certificate in the amount of two-dollars (\$2) to Baskin Robbins® as an incentive for their participation in this study

CONTACT: If you have any questions or concerns you may contact Dr. Rosemary McCaslin, Professor of Social Work at 909-537-5507 or email at rmccasli@csusb.edu

RESULTS: You may receive results of this study upon completion in December 2015 from the Pfau Library located at 5500 University Parkway San Bernardino, CA 92407; 909-537-5091.

CONFIRMATION STATEMENT: By placing a check mark in the box below, I acknowledge that I have been informed of and that I understand the nature and purpose of this study. I understand that I must be 18 years of age or older to participate in your study. I have read and understand the consent document and agree to participate in your study.

Place a check mark here []

Today's date: _____

APPENDIX C
DEBRIEFING STATEMENT

DEBRIEFING STATEMENT

While completing the survey regarding stress custodial grandmothers face while raising children with disabilities, you were asked questions regarding your family, well-being, age, education and sources of income. The purpose of this research is to explore ways custodial grandmothers of children with disabilities can practice self-care in order to lower their stress levels. This research may help grandmothers learn of available resources as well as educating professionals about the dynamics of being a caregiver and the need for grandmothers to access resources. This research is being conducted by graduate student, Kanika Kisero. For the study you participated in, be assured there was no deception involved. All of the information collected will be used to conduct research and will properly be discarded once the study is complete. If you have questions or concerns based on this survey you just completed, you may contact Dr. Rosemary McCaslin, Professor of Social Work for California State University San Bernardino at 909-537-5507.

If for any reason taking this survey caused minor distress, please refer to these resources: 24-hrs Crisis Hotline at 1-800-273-TALK or County of San Bernardino Department of Behavioral Health at 1-888-743-1478.

Your participation in this research was greatly appreciated. Thank you.

Sincerely,

Kanika Kisero

APPENDIX D
PERMISSION LETTER



Helping Hands Kinship Support Services
16519 Victor Street Suite 404
Victorville, CA 92395

June 26, 2014

Dr. Rosemary McCaslin
Department of Social Work
California State University, San Bernardino
5500 University Parkway
San Bernardino, CA 92407

Dr. McCaslin:

This letter is to notify the School of Social Work at California State University, San Bernardino, that Kanika Kisero has obtained consent from Helping Hands Kinship Support Services, a program under Mental Health Systems, to conduct research for her research project entitled, "Custodial Grandmothers Raising Children with Disabilities and the Stressors They Face".

Sincerely,

A handwritten signature in blue ink that reads "Myrtle Cassell". The signature is written in a cursive style.

Myrtle Cassell
Program Manager
Helping Hands Kinship Support Services

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APPENDIX E

FLYER



Calling on GRANDMOTHERS!!

My name is Kanika Kiseru and I'm a graduate student at California State University, San Bernardino. Research is being conducted on the possible stressors grandmothers face while raising children with disabilities. Some of these disabilities can be autism, intellectual disabilities, epilepsy, cerebral palsy, ADHD and/or physical disabilities. The Institutional Review Board's Sub-committee for the School of Social Work at California State University, San Bernardino, has approved this study. I need your help by taking a brief survey for this study. Surveys will be at Mental Health Systems in the front office and should not take longer than 15-20 minutes to complete. A \$2 gift certificate to Baskin Robbins® ice cream store will be given to those who participate.



If you have questions please call Dr. Rosemary McCaslin @
909-537-5507
THANK YOU

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