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Practice Article

Kinship Diversion in the District of Columbia:
A Review of Local Practice to Inform National Policy

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Abstract
Like other child protection agencies throughout the United States, the District of Columbia Child and Family Services Agency is engaging in a practice commonly known in the child welfare community as "kinship diversion." This practice is typically defined as an alternative to foster care that is utilized by child welfare agencies to informally place children with relatives when they cannot remain safely at home with their parents. There are many reasons to look to kin to care for abused and neglected children, most importantly to keep them from being placed with people they do not know at an already traumatic time in their lives. What is often not understood is that relatives and fictive kin can be approved as foster parents and can receive essential financial assistance and supportive services to help safely raise these children, who often have significant needs. By contrast, kinship diversion does not protect abused and neglected children from harm nor does it help stabilize the family unit financially or emotionally. It is thus not surprising that many diverted children are at risk of being re-traumatized and returned to the abusive or neglectful parent. We contend that the safety of abused and neglected children who are diverted in D.C. and nationwide is imperiled because child protection agencies do not oversee or manage what happens to them. Recommendations for identifying and implementing best practices in this area to protect diverted children are explored.

Keywords: children, kin, kinship, caregiver, abuse

Like many state and local child protection agencies throughout the United States, the District of Columbia Child and Family Services Agency ("CFSA") is engaging in a practice known in the child welfare community as "kinship diversion." This practice is often defined as an alternative to foster care, "when a child welfare agency facilitates the placement of a child with relatives or fictive kin when that child cannot remain safely at home with his or her parents" (Malm & Allen, 2016, p. 1; *see also* Berrick & Hernandez, 2016; Wallace & Lee, 2013). There are many reasons to look to relatives to care for children who cannot remain safely at home, most importantly to keep children from being placed with people they do not know at an already

traumatic time in their lives. Indeed, research predominantly shows that abused and neglected children raised by relatives have better outcomes than those raised by non-relatives (Cheung, Goodman, Leckie, & Jenkins, 2011; Falconnier et al., 2010; Fechter-Leggett & O'Brien, 2010; Generations United, n.d.; Koh, 2010; Rubin et al., 2008; Winokur, Crawford, Longobardi, & Valentine, 2008; Winokur, Holtan, & Batchelder, 2014).[1]

Federal law has historically mandated that when children cannot remain safely at home, states document efforts to find placements with fit and willing relatives, give preference when making placement decisions to adult relatives over non-relatives, notify relatives when a child is removed from home, and have family meetings to help children stay safely with family members.[2] Federal law also encourages states to waive non-safety-related foster parent licensing standards for relatives.[3] In D.C., relatives can be approved for temporary foster parent licensing on a fast track so that abused and neglected children can be placed quickly.[4]

However, rather than license relatives as foster parents, child protection agencies, including CFSA, are increasingly relying on kinship diversion. Defenders of this practice contend that it allows the family to remain in control of decisions regarding their own child and keeps the child out of the foster care "system" (Annie E. Casey Foundation, 2013). However, unlike foster care, kinship diversion does not provide abused and neglected children and their families with necessary protections, financial assistance, and supportive services (Wallace & Lee, 2013). This is particularly problematic because kinship caregivers are more likely to live in poverty and have poor health and education, and the children in their care typically have significant emotional and physical needs (Annie E. Casey Foundation, 2012; Bavier, 2011; Golden & Hawkins, 2012; Wallace & Lee, 2013).

In the context of kinship diversion, children may not receive mental health and other services for trauma recovery; birth parents are not required to get supports and services to resume safely caring for their children; kin caregivers do not receive sufficient (if any) financial, respite, and other benefits to care for these children; and there is no mechanism for safely reunifying the family or, if that is not possible, achieving permanency for the children (Mauldon, Speiglman, Sogar, & Stagner, 2012). It is, thus, not surprising that many diverted children are at risk of being returned or exposed to the abusive or neglectful parent without safeguards to prevent future harm (Annie E. Casey Foundation, 2013). Further, many child protection agencies, including CFSA, do not keep track of children in kinship diversion arrangements or their outcomes. As a result, it is unknown what happens to these abused and neglected children.

The recently passed Family First Prevention Services Act of 2017 ("Family First Act")[5] could address some of the failings inherent in kinship diversion. Specifically, under that law, states may elect to use Title IV-E funds to provide identified, evidence-based, well-supported, and trauma-informed services and programs for not more than 12 months to prevent children

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[1] Note, several more recent research studies have raised concerns about the well-being of children in certain types of relative care arrangements (Anderson, & Falleson, 2015; Font, 2015; Garcia et al., 2015; Rufa & Fowler, 2016; Stein et al., 2014; Wu, White, & Coleman, 2015; Xu & Bright, 2018).

[2] Adoption and Safe Families Act of 1997, Pub. L. 105-89, 111 Stat. 2115 (1997) and Fostering Connections to Success and Increasing Adoptions Act of 2008, Pub. L. 110-351, 122 Stat. 3949 (2008).

[3] Fostering Connections to Success and Increasing Adoptions Act of 2008, Pub. L. 110-351, 122 Stat. 3949 (2008) and Family First Prevention Services Act of 2017, enacted as Division E, Title VII of the Bipartisan Budget Act of 2018) Pub. L. 115-123, 132 Stat. 64 (2018).

[4] D.C. Mun. Reg. tit. 29, §6027.

[5] Family First Prevention Services Act of 2017, (enacted as Division E, Title VII of the Bipartisan Budget Act of 2018) Pub. L. 115-123, 132 Stat. 64 (2018).

from entering foster care. Such programs and services are limited to mental health, substance abuse prevention, and in-home parent skill-based programs. States must have a prevention plan in place for each child at imminent risk of removal to foster care. Each prevention plan must identify the strategy for the child to remain safely at home or in a kinship placement and the services to be provided to the parent, child, and kin caregiver, as applicable. If the prevention plan does not successfully create a safe environment for the child after 12 months, the option to remove the child to foster care is preserved. States will be required to monitor and oversee the safety of children who receive these services or programs and track their outcomes long-term. However, the Family First Act does not provide any financial subsidy for kin caregivers in this scenario, and it remains to be seen how states that elect to participate will oversee and monitor the provision of services to children and families and whether there will be successful outcomes.

CFSA's Kinship Diversion Practices

While this article primarily focuses on CFSA's use of kinship diversion and its impact on abused and neglected children in D.C., the discussion below provides a useful illustration of issues that arise with these arrangements in general and as employed by other jurisdictions with similar practices. D.C. is not alone in the practice of kinship diversion: while good data is scarce, this practice or similar variants are common in many jurisdictions across the country (Annie E. Casey Foundation, 2013; Malm & Allen, 2016; Wallace & Lee, 2013).

How CFSA Utilizes Kinship Diversion

The following description of how CFSA utilizes kinship diversion is based primarily on information reported to D.C. child welfare advocates by relative caregivers and former CFSA social workers.

- CFSA receives a call on its child abuse and neglect hotline and investigates the report of child abuse or neglect;
- CFSA makes a finding of abuse or neglect and the facts of the case suggest that the child is at high risk and cannot be protected in the home;
- A relative (usually a grandparent) or close family friend (fictive kin) agrees to care for the child with the birth parent's apparent consent. This agreement typically occurs at a family team meeting (or similar meeting) where CFSA is present and still involved with the family;
- CFSA drafts a safety plan delineating the terms of the arrangement; and
- CFSA closes its internal case without any court involvement, and the kin caregiver takes care of the child informally.

As noted above, kinship diversion arrangements usually are established at a family team or similar meeting. This meeting occurs at a time of significant stress, which can make it difficult for family members to fully understand what is happening and make prudent decisions. Based on kin caregiver reports about the meeting, CFSA typically encourages the birth parent and potential kin caregiver to agree to kinship diversion to prevent placement of the child in foster care.

While CFSA contends that it informs potential kin caregivers of the option to pursue foster care licensure, many of those caregivers later report they did not know about or fully understand this option and the benefits of doing so. This lack of understanding is exacerbated because CFSA does not provide kin caregivers with an easily understandable written document that discusses all available placement options and the advantages and disadvantages of each,

including the financial supports available. Further, neither the parent nor the kin caregiver has an advisor present who can explain these very complex issues. According to child welfare advocates, some kin caregivers have indicated they would have sought licensure as foster parents if they had been aware of and/or fully understood that option at the meeting. Unfortunately, this lack of access to essential information for kin caregivers, and in some cases active dissuasion from becoming a licensed foster parent, is not unique to D.C. (Annie E. Casey Foundation, 2013; Malm & Allen, 2016; Wallace & Lee, 2013).

Even if kin caregivers are informed about the opportunity to become foster parents, they often have concerns about how burdensome the process may be. D.C., like many other jurisdictions, has stricter foster parent licensing standards than those required by federal law. As a result, many kin will not be able to qualify as foster parents. D.C. provides for waivers of certain non-safety-related foster care licensing requirements at CFSA's sole discretion,[6] but not all states currently permit such waivers. In addition, foster parents must complete training before becoming fully licensed. D.C.'s foster parent licensing requirements are among the most rigorous in the country (Beltran & Epstein, 2012).[7]

CFSA does explain to kin that they can file for custody of the child in court[8] and refers them to a legal services organization for assistance. However, if the parent does not consent, the kin caregiver must overcome rigorous legal requirements to be granted custody by a court.[9] Specifically, under D.C. law, the kin caregiver must show by *clear and convincing evidence* that the parent is unwilling or unable to care for the child or it would be detrimental to the child's physical or emotional well-being for the parent to do so, *and* that it is in the best interests of the child to grant the kin caregiver custody.[10] This standard is reflected in most states' third-party custody statutes, and the United States Supreme Court has reaffirmed a parent's fundamental Constitutional right to raise his or her children and "to make decisions concerning their care, custody and control."[11] Significantly, if the parties and the child are unpresented, the D.C. custody court may not be presented with all information that could be relevant to its decision-making. This makes it even more difficult for unrepresented kin caregivers to overcome the high bar to be granted custody.

How CFSA Strategy Results in a Perverse Incentive to Use Kinship Diversion

In 2012, CFSA adopted a strategic agenda called the Four Pillars. The "Front Door" pillar states that:

> Children deserve to grow up with their families and should be
> removed from their birth homes only as the last resort. Child
> welfare gets involved only when families cannot or will not take
> care of children themselves (CFSA, 2018a).

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[6] *Id.* tit. 29, § 6000.5. While D.C. law provides for waivers of non-safety-related licensing requirements, we were unable to identify information about CFSA's current use of such waivers.

[7] D.C. requires 30 hours of pre-service training to become a licensed foster parent and another 30 hours of in-service training post-licensure. *Id.* tit. 29, §§ 6026.2 and 6026.5.

[8] Relatives and other third parties may file for custody of a child in D.C. pursuant to the Safe and Stable Homes for Children and Youth Amendment Act of 2007 if they meet certain jurisdictional and standing requirements. See D.C. Code § 16-831.01 *et seq.*

[9] *Id.* § 16-831.01 *et seq.*

[10] *Id.* § 16-831.06.

[11] Troxell v Granville, 590 U.S. 57 (2000).

In practice, CFSA has been striving to "narrow" the Front Door (CFSA, 2018a). The result has been a dramatic decrease in the number of D.C. children removed from their homes. At the end of fiscal year 2006, there were 2,313 children in foster care; by the end of fiscal year 2017, that number had fallen by 61% to 898 children, with a 9% decrease between fiscal years 2016 and 2017 alone (CFSA, 2018a).

As part of its strategy, CFSA sets internal benchmarks for continuing reductions in the size of the D.C. foster care population (CFSA, 2018a). These benchmarks appear financially motivated and arbitrary, as they do not seem to be related to real-life risk factors such as the number of children born in D.C. in a given year or the amount of crime, drug use, homelessness, poverty, domestic violence, mental illness, or other indicators that influence the rate of child abuse and neglect (Annie E. Casey Foundation, 2013; Child Trends, 2016).

CFSA's arbitrary benchmarks for reducing the D.C. foster care population provide CFSA with a perverse incentive to use kinship diversion, rather than attempting to license kin caregivers as foster parents. Indeed, kinship foster care is underutilized in D.C. As of June 30, 2017, only 22% of D.C. children in out-of-home care (which includes foster care as well as group homes, institutional, pre-adoptive homes, and therapeutic placements) were in kinship foster care (Center for the Study of Social Policy, 2017); nationally, 32% of children in out-of-home placements were in kinship foster care arrangements as of September 30, 2016 (Children's Bureau, 2017).

We note that it is unclear whether kinship diversion is even legally permissible under D.C. law. Specifically, if a report of abuse or neglect is substantiated and the child is at risk, CFSA is authorized to do the following: first, it must undertake all "reasonable efforts . . . to prevent or eliminate the need for removing the child;" and second, if the child cannot be "adequately protected" in the home, then CFSA is required to remove the child to foster care.[12] Accordingly, once CFSA determines that a child cannot be protected in the home through the provision of services, the relevant statute does not give CFSA leeway to arrange for the child to be taken out of the unsafe home and transferred to the care of a third party (in this case, a relative or fictive kin) without the protections and supports associated with foster care. For its part, CFSA denies engaging in kinship diversion and has no policies addressing it. Significantly, if CFSA seeks to participate in the Family First Act preventive services and programs for diverted children, presumably a change in D.C. law and policies would be required. This may be the case in other states as well.

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CFSA's Kinship Diversion Practices
Create Serious Dangers for D.C. Children

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Research shows that the decision to utilize kinship diversion in lieu of foster care is not dependent on maltreatment type or severity, but rather on whether there is a willing relative available to take the child (Annie E. Casey Foundation, 2013; Malm & Allen, 2016). Accordingly, a child in a kinship diversion arrangement could have experienced the same type and/or severity of abuse or neglect as another child who is placed in foster care. In this context, the abused and neglected child diverted to kinship care is at risk of re-traumatization because, as discussed below, kinship diversion does not provide the considerable protections and supports associated with foster care.

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[12] D.C. Code §§ 4-1301.09a and 4-1303.04(c).

Diverted D.C. Children Are Deprived of the Safeguards and Supports of Foster Care

When a child protection agency places a child in foster care, it must take certain steps to ensure the safety of the child in the foster home. Set forth below are those generally utilized by CFSA:

- Conducting criminal background and child protection register checks on the foster parent and others adults living in the home; performing a health and safety assessment of the foster parent's home; and evaluating whether the foster parent can provide a safe and secure environment for the child;
- Requiring the foster parent to meet conditions related to the child's sleeping arrangement, health care, education, and appropriate discipline of the child;[13]
- Preparing a case plan for the child and the family and periodically reviewing that case plan;
- Assigning a social worker to meet with the child and family on a regular basis to oversee the case plan and ensure all parties are complying;
- Providing and arranging for services and supports for the child, birth parent, and foster parent; and
- Providing a safe pathway for the child to be reunified with the birth parent or, if that is not possible, to be placed in a permanent home.[14]

In other words, for a child in foster care, the agency must review the placement at the outset and on an ongoing basis to ensure that the child is safe, the birth parent's rights are protected, and appropriate services are provided to stabilize the child and family. This supervision furthers the principal goal of foster care==for the child to be reunified with the birth parent once the safety issues that led to abuse or neglect have been addressed.[15]

None of the above steps are required in a kinship diversion arrangement. When CFSA diverts a child, CFSA does not routinely do a home study to ensure that the kin caregiver's residence and neighborhood are safe, collect basic information about the kin caregiver and others living in the home, and/or ensure the kin caregiver has the means and ability to care for the child.[16] CFSA's failure to assess these socioeconomic and psychosocial factors is particularly concerning because, as noted above, kinship caregivers are more likely to live in poverty and have poor health and education, and the children in their care typically have significant emotional and physical needs (Annie E. Casey Foundation, 2012; Bavier, 2011; Golden & Hawkins, 2012; Wallace & Lee, 2013). Research shows that these factors result in worse outcomes for children over time (Rufa & Fowler, 2016).

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[13] Children in foster care have identified rights to, among other things, appropriate housing, food, clothing, education, health care, privacy, extracurricular activities, transportation, as well as the right to be free from abuse or neglect. D.C. Mun. Reg. tit. 29 § 6004.1.

[14] See, e.g., D.C. Code §§ 4–1302.03, 4-1303.04, 4-1305.02, 4-1401 *et seq.*, 7-2105, 16-2313, 16-2320; D.C. Mun. Reg. tit. 29 § 6000 *et seq*.

[15] See, e.g., D.C. Code § 4-1301.09a(b).

[16] CFSA has represented to child welfare advocates that it relies on its social workers' judgment and does not systematically vet every such arrangement. A lack of consistent or uniform policies in this area has been documented by researchers in other jurisdictions as well (Malm & Allen, 2016).

Furthermore, CFSA does not provide even minimal post-diversion services or supports to the child, birth parent, or kin caregiver.[17] CFSA takes the position that it has no further responsibility for the child or the family because the parent has purportedly consented to the arrangement and the child is no longer in an unsafe home with an abusive or neglectful parent. However, without CFSA oversight and accountability, the needs of the child, birth parent, and kin caregiver can go unmet, and there is no process for safely reunifying the family.

CFSA also does not oversee what happens to diverted children (CFSA, 2018c). The absence of ongoing monitoring of these children is particularly important as there are indications that kinship diversion practices do not necessarily lead to the hoped-for outcomes (Font, 2015; Stein et al., 2014). With the recent adoption of the Family First Act, there exists the possibility that D.C. and other jurisdictions could begin monitoring and evaluating the efficacy of a form of supported kinship diversion. It remains to be seen, however, whether they will opt to participate in the Family First Act prevention services and programs and, if so, what the data and performance measures will reveal.

Finally, unless granted legal custody by a court, the safety plan does not accord the kin caregiver any legally enforceable rights to care for the child, and so the birth parent can retrieve the child at any time. The kin caregiver also has not been specifically granted the right to obtain medical care or information for the child or the right to apply for certain public benefits on behalf of the child. Kin caregivers also report having trouble enrolling children in school (Miller & Donohue-Dioh, 2017). While CFSA often encourages kin to file for custody of the child in court, the kin caregiver may not want to sue the birth parent for custody or may not have legal standing to do so.[18] Further, there is no guarantee that a court will grant the kin caregiver custody, especially if the parent no longer consents to the arrangement.

D.C. Kin Caregivers Receive Limited Financial and Other Benefits to Raise Diverted Children

D.C. foster children are entitled to various benefits, such as clothing vouchers; aftercare programs; college preparation programs, college tours, and financial aid; grants for college or vocational training programs; housing programs; and intensive programs for transition to adulthood.[19] These benefits are not available to diverted children. Further, foster parents receive a maintenance payment to assist with the costs of raising the child, such as clothing, food, and school supplies. Foster care subsidy rates in D.C. for 2018 range from $1,140 to $1,995 per 30-day period per child, depending on the special needs of the child and whether the child is a teen parent. Foster care subsidy rates are adjusted each year for cost-of-living increases. There is no financial means test for foster parents to receive the maintenance payments, and other benefits received by the household are not deducted from the rate.

Defenders of kinship diversion in D.C. contend that grandparents and other relatives who care for children informally can receive a subsidy under the D.C. Grandparent Caregivers Program ("GCP"). The GCP was enacted in 2005 and D.C. remains one of only a few jurisdictions to provide an ongoing monthly subsidy to relative caregivers (whether part of a kinship diversion arrangement or otherwise). Based on the legislative history, the purpose of the

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[17] At the family team meeting when the diversion takes place, CFSA typically helps the family develop a safety plan that includes voluntary services and may provide the family with a referral to a governmental or community-based service provider.

[18] D.C. Code § 16-831.02.

[19] D.C. Mun. Reg. tit. 29 § 6004.1.

GCP was to address "the disparity of financial assistance provided to foster parents who care for the District's adjudicated children" as compared to grandparent caregivers "in spite of the important role they have risen to accept" (Council of the District of Columbia Committee on Human Services, 2005). While clearly an innovative law, we believe the GCP, as currently implemented, fails to achieve this purpose. The original law provided that the amount of the GCP subsidy would be "no less than the regular daily rate of the subsidy for a long-term permanent guardianship."[20] However, over the years the law was amended and now provides that the GCP subsidy be not less than 66% of the permanent guardianship regular daily rate.[21] After offsets of TANF and SSI benefits,[22] the average benefit was only $594.90 per 30-day period per child for fiscal year 2017 (CFSA, 2018b), at best half the D.C. guardianship rate[23] (CFSA, 2018a). The rate has essentially remained stagnant since 2012 (CFSA, 2018b), so it does not account for cost-of-living increases.

Finally, there are significant eligibility restrictions for acceptance into the GCP. Specifically, eligibility is limited to grandparents, great grandparents, great aunts and great uncles. Other categories of relatives and fictive kin are not eligible to apply.[24] Caregivers must live in D.C., show proof they have been the primary caretakers of the child for the previous six months without a parent present in the home,[25] undergo criminal and child protection register checks (with no waivers available), and have total household income below 200% of the Federal Poverty Level.[26] Caregivers also must be recertified each year and must apply for TANF for the child,[27] which many are reluctant to do because it requires them to authorize D.C. to sue the parents for child support (Office of the Attorney General for the District of Columbia, n.d.).

We believe that D.C. should be commended for establishing a program to support kin who care for children informally and other states should follow its example. However, to meet the needs of kin caregivers, the amount of the subsidy should be increased to be commensurate with the D.C. guardianship/foster care subsidy rate. The requirement to offset other benefits from the rate should be eliminated and eligibility should be expanded to the full universe of relative caregivers. Research shows children living with grandparents have a higher risk of poverty than other children and the most pressing need of kinship caregivers is financial (Geen, 2004; Miller & Donohue-Dioh, 2017; Pac, Waldfogel, & Wimer, 2017; Sampson & Hertlein, 2015). By contrast, "foster care payments likely play an important role in reducing the risk of poverty" for foster children (Pac et al., 2017).

Diverted D.C. Children Subject to Instability and Exposure to Future Harm

When CFSA engages in kinship diversion, there is a risk that the kin caregiver will return the child to the abusive or neglectful parent within the first months of the arrangement because the kin caregiver is unable or unwilling to continue to care for the child, the parent requests the child's return, and/or the child wants to go home (Annie E. Casey Foundation, 2013; Rufa & Fowler, 2016). Even if the child continues to live with the kin caregiver, there may be no stability for the child because, unless the kin is granted custody by a court, the birth parent has

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[20] D.C. Code § 4–251.04(b) (2005).

[21] *Id.* § 4–251.04(b).

[22] *Id.* § 4-251.04(c).

[23] Currently, the guardianship and foster care rates in D.C. are the same.

[24] D.C. Code § 4–251.01(2).

[25] There are exceptions if the parent is a minor or disabled. *See Id.* §§ 4–251.03(a)(3)(A)-(C).

[26] *Id.* § 4–251.03(a)(5).

[27] *Id.* §§ 4–251.03(a)(7) and (b)(1).

the right to come get the child at any time. In other words, there is no long-term plan for the child or assurances of a permanent stable home (Annie E. Casey Foundation, 2013).

Instability of living arrangement and recurring exposure to abuse or neglect can have long-term adverse consequences for a child. Scientific research shows that such repetitive highly stressful experiences can alter the normal development of a child's brain and change the chemistry that encodes the genes in brain cells (Children's Bureau, 2012; Children's Bureau, 2015). This, in turn, results in an increased risk for later mental illnesses, including generalized anxiety disorder and major depressive disorder; increased risk for physical ailments, such as asthma, hypertension, heart disease and diabetes; and increased risk of antisocial behavior, such as substance abuse and violent crime (Felitti et al., 1998; National Scientific Council on the Developing Child, 2010).

Recommendations to Ensure Better Outcomes for Children

We discuss below recommendations CFSA and other state and local child protection agencies should consider implementing to improve the safety and well-being of diverted children.

Licensing Kin as Foster Parents

When a child protection agency is considering kinship diversion for a child, it should ensure that all potential kin caregivers understand their rights to become foster parents and the benefits of doing so. This step should be accomplished by providing kin caregivers with accurate and complete information about the legal and financial implications of becoming a foster parent, as well as making an advocate available to assist with decision-making.

Further, states should revise their foster care licensing requirements to allow for waivers of non-safety-related standards for kin caregivers and remove unnecessary requirements so more kin can qualify without the need for a waiver (Kinship Care Summit, 2017). Consideration also should be given to whether those seeking to become kin foster parents should be required to satisfy the same training requirements as non-kin foster parents.

Increased licensing of kin caregivers as foster parents will ensure that they can provide a safe and nurturing home environment and have the financial and other supports needed to care for the child (Rufa & Fowler, 2016). A child placed in a licensed home is at lower risk of re-traumatization because he or she will only be returned to the birth parent once the factors associated with the abuse and neglect have been ameliorated. If reunification is not possible, the child will have the security of knowing that he or she will not be returned to an unsafe home and can have permanency with kin.

In-Home Case to Include the Whole Family

Following and expanding upon the Family First Act, we recommend that when a child protection agency engages in kinship diversion, it should open an in-home case to include the whole family. Under this scenario, the agency would assign a social worker to oversee and coordinate services to the birth parent to address the factors that led to abuse or neglect, to the child to address trauma, and to the kin caregiver to support the safety and stability of the placement. In addition, all relative and fictive kin caregivers should be eligible to receive a subsidy, like the D.C. Grandparent Caregiver Program subsidy, but in an amount commensurate with the jurisdiction's foster care subsidy rate. The child would be able to return home once the birth parent, kin caregiver, and child have met all safety and well-being requirements. If those

requirements cannot be met, then foster care with the kin caregiver should be initiated whenever possible. A few jurisdictions are already experimenting with forms of this approach, known as "supported diversion" (Annie E. Casey Foundation, 2013).

Appropriate Tracking of Diverted Children and Families

The lack of data about the scope and effectiveness of kinship diversion is a problem throughout the country that should be addressed (Berrick & Hernandez, 2016). The Family First Act has introduced the concept of states monitoring and collecting data on children in kinship diversion arrangements. We contend that all state child protection agencies should track abused and neglected children in these arrangements and assess their outcomes, regardless of whether the state opts to participate in the Family First Act prevention services program.

The types of information that should be tracked include: (a) the age, gender, race and ethnicity of each diverted child, the nature of the child's relationship to the kin caregiver, the family's history of involvement with the child protection agency, and what, if any, services, were provided to the family before and after the child was diverted; (b) what percentage of kin caregivers initiate custody proceedings in court for children diverted to their care; (c) how many diverted children live with kin pursuant to a court custody order within three months, six months, and one year after diversion; (d) how many of these children were returned to the parent within three months, six months, and one year after diversion; (e) whether those returns were consistent with the requirements of the safety plan, e.g., was the child safely returned; (f) how many diverted children were the subject of a child protection hotline call within three months, six months, and one year after diversion, and where was the child living at the time of the report; (g) of these hotline calls, how many did the child protection agency accept for further action, such as an investigation; (h) for those reports investigated, how many resulted in a substantiated finding of abuse or neglect and where was the child living at the time; and (i) whether particular services or supports correlate with the success of each diversion arrangement. We recognize that there may be additional or different ways to measure outcomes for diverted children that also should be considered.

Conclusion

Within the national child welfare community, there is a growing consensus that "kinship diversion without appropriate attention to safety and support hurts children and families…" (Annie E. Casey Foundation, 2013; Wallace & Lee, 2013). We contend that the safety of abused and neglected children who are diverted in D.C. and nationwide is imperiled because child protection agencies do not oversee or manage what happens to them. We believe child protection agencies must ensure kin caregivers understand their rights to become foster parents and streamline the requirements for them to qualify. Alternatively, when a child is diverted to live with kin, child protection agencies should open an in-home case to include the whole family, provide a financial subsidy to kin caregivers, and assign a social worker to coordinate care and ensure the child is stable and only returned to the birth parent when all safety concerns have been addressed. Finally, we propose that states track the demographics, needs, and outcomes of children, kin, and families in kinship diversion arrangements to determine best practices for ensuring the safety and well-being of diverted children.

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Research Article

Conflicts, Concerns and Family Circumstances in Custodial Grandmothers Over 8 Years

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Abstract

Although many grandmothers raising grandchildren experience transitions in their roles as family strains and circumstances change, little longitudinal data has been examined. This qualitative study assessed the relationships between custodial grandmothers' appraisals of their family conflicts and concerns and family circumstances across eight years. Participants were 35 Ohio grandmothers who were raising their grandchildren in 2006-2007 and provided additional self-report survey data in 2008-2009 and 2014-2015. Data were gathered from open-ended questions that were analyzed through conventional content analysis. The reported concerns were financial and emotional difficulties, grandchildren outcomes, mental and physical health of the grandchild and other family members, and difficulties coping with visitations and custody issues. Concurrently, grandmothers experienced several transitions in their caregiving status and family circumstances over time. Implications of the results are also discussed.

Keywords: skipped generation families, family transitions, family strains, qualitative analysis, intergenerational relationships

According to the 2012 American Community Survey, more than 2.7 million grandparents live in the same household as their grandchildren, with 39% of them raising grandchildren aged 18 or younger (Ellis & Simons, 2014). Most research has been cross-sectional and focused on the mental and physical health effects of such caregiving in grandmothers and, to a lesser extent, in grandchildren. The limited longitudinal data is primarily quantitative, which cannot adequately contextualize the ongoing conflicts and concerns of grandmothers raising grandchildren or the complexity of their family and living situations over time. Therefore, this qualitative study provides a perspective of the trajectory of grandmothers raising grandchildren and examines how conflicts and concerns change over time and reflect the living situation of the family.

Stress, Family Concerns, and Conflicts

Grandmothers in a parental role, which is usually assumed abruptly and is inconsistent with grandmothers' previous expectations (Goodman & Silverstein, 2006), exposes them to stressful situations that are likely different, greater, and more unremitting than those experienced by non-caregivers to grandchildren or grandmothers living in multigenerational families (Musil, Warner, Zauszniewski, Wykle, & Standing, 2009; Musil, Jeanblanc, Burant, Zauszniewski, & Warner, 2013). Grandmothers raising grandchildren perceive more difficulties in family functioning (Musil, Warner, Zauszniewski, Jeanblanc, & Kercher, 2006), and more family strains related to adult children's substance abuse, negligence, health and mental issues, death, and incarceration, than grandmothers living in multigenerational homes or who are non-caregivers to grandchildren (Crewe, 2012).

In these situations, grandparents not only have to cope with their grandchildren's emotional distress, but also with their emotions about their children's failures. In fact, Sampson and Hetlein (2015) reported that grandparents raising grandchildren often feel resentment and disappointment with their adult children's' choices (drug abuse, being incarcerated, suffering from AIDS/HIV disease, etc.) which, in turn, is perceived as their own failure at raising their now-adult children. In cases where the adult child has died, grandparents have shown high levels of distress because of having to deal with their grandchildren's grief as well as their own.

This high rate of difficulties in grandparent-headed, or skipped generation, families, is associated with greater levels of stress in grandmothers. Roughly, 40% of grandmothers raising their grandchildren showed psychological or emotional distress within the clinical range (Kelley, Whitley, & Campos, 2013). The main sources of grandmothers' stress are related to family relationships (Sands & Goldberg-Glenn, 2000), grandchildren's behavioral and mental problems (Doley, Bell, Watt, & Simpson, 2015; Gladstone, Brown, & Fitzgerald, 2009; Hayslip, Blumenthal, & Garner, 2014), and worries about the grandchildren's future (Gladstone et al., 2009). As many as 86% of grandmothers described grandchildren's care as challenging (Crowther, Huang, & Allen, 2015).

Studies show more emotional, social and physical problems in grandchildren raised by grandmothers compared with those raised by their biological parents. Billing, Ehrle, and Kortenkamp (2002) reported that 13% of grandchildren raised by their grandmothers had emotional and behavioral problems, compared with 7% of grandchildren raised by their biological parents. Others also report high rates of behavioral and emotional problems, special needs and academic underachievement among these grandchildren (Shakya, Usita, Eisenberg, Weston, & Liles, 2012). These problems occur to a greater extent when grandchildren show externalizing behaviors, such as opposition, hyperactivity, or disobedience (Sands & Goldberg-Glenn, 2000), which are more common when children were abused or had mothers with depressive symptoms (Buckinham-Howes, Oberlander, Hurley, Fitzmaurice, & Black, 2011). However, mental and physical health problems in children cared for by grandparents are less frequent than those in non-family foster care (Winokur, Holtan, & Batchelder, 2014).

Grandmothers raising grandchildren face significant challenges related to their adult children (Shakya et al., 2012), including disputes over grandchildren's custody (Crewe, 2012), disruption of the child after visitation (Sands & Goldberg-Glen, 2000), conflicting feelings toward the adult child (Gladstone et al., 2009), and adult children's emotional problems (Musil et al., 2006). Grandmothers raising grandchildren often report difficulties in performing their roles, which reduces their satisfaction with the grandparent-grandchild relationship (Hayslip, Emick, Henderson, & Elias, 2002), and contributes to ongoing conflicts and concerns in the family.

Changes in Family Circumstances

In addition to the natural developmental changes in families, skipped generation families often experience changes in their family circumstances and structure, which may increase vulnerability for family members (Standing, Musil, & Warner, 2007). Although 40% of grandmothers raised their grandchildren for more than five years (Ellis & Simons, 2014), two-thirds of the grandmothers in the Health and Retirement Study experienced changes in their family circumstances over time (Blustein, Chan, & Guanais, 2004). Using the National Survey of Families and Households data, Szinovacz, De Viney, and Atkinson (1999) found that 52% of grandmothers living with grandchildren at the beginning of their study had grandchildren who moved in, and 19% had grandchildren who moved out after two years. Hughes, Waite, LaPierre, and Luo (2007) reported that 50% continuously lived in skipped generational households, while nearly 18% stopped living in this type of household after two years. These studies provide a broad picture of the often transitory nature of grandparent caregiving, but they are unable to detail the grandmothers' experiences as their family situations unfold.

While grandmothers raising grandchildren have many stresses and concerns rooted in the context of the family situation, these circumstances do not remain constant. Previously identified reasons why grandmothers changed their caregiving status from raising grandchildren to non-caregivers were the resolution of family problems (e.g., parents regain grandchildren's custody or finish drug addiction treatment) or an increase in family difficulties (e.g., grandmothers' health problems or grandchildren not accepting rules). While describing these transitions, grandmothers have expressed ambivalent feelings (loss and relief), but greater personal freedom (Standing et al., 2007).

There is scant literature describing the circumstances, concerns, and conflicts that grandmothers in skipped generation families experience over time, and this study adds to that literature. This study spans a period of eight years, beginning when the grandmothers were raising the grandchildren while the parents did not live in the same home as the grandmother and grandchild(ren). The study qualitatively describes in greater depth the family circumstances, conflicts, and concerns of a sample of grandmothers raising grandchildren over an eight-year time period.

Methods

This is a secondary analysis of data from a longitudinal study of grandmothers´ caregiving to their grandchildren. This qualitative study used content analysis to describe the family conflicts and concerns that were reported by grandmothers who were raising grandchildren in skipped generation homes, and how these conflicts, concerns, and circumstances change over time.

Content analysis is "a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns" (Hsieh & Shannon, 2005, p. 1278). Specifically, we used conventional content analysis because of its recommendation when researchers aim to develop knowledge and a better understanding of a social phenomenon supported by limited theory or literature (Hsieh & Shannon, 2005). For this reason, conclusions are derived from the data instead of previous theories or researchers' assumptions (Krippendorf, 1980).

Participants

This secondary analysis focuses on 35 grandmothers who had participated in the final three waves of a six-wave study of grandmothers as caregivers to grandchildren that began in 2001 and continued until 2014-2015 (for more information on the sample of the larger study, see note[1]). We examined data from grandmothers who had been raising one or more grandchildren for at least five years, were raising a grandchild in 2006-2007 (when specific questions of relevance were asked), and participated in the final three study waves (2006-2007, 2008-2009, and 2014-2015). This analysis allows us to look at a sample of grandmothers and prospectively watch them and their families across eight years. Grandfathers were excluded from the study since grandmothers tend to develop a role of principal caregiver.

Grandmothers were recruited from across the state of Ohio using random digit dialing (RDD) and convenience sampling from support groups and word of mouth (see Musil et al., 2006, for details). The original study included 183 grandmothers raising grandchildren at baseline, and 41 of them continued through to 2014-15, representing a 22% continuation over 14 years of the larger study. Of the original 183 grandmothers raising grandchildren, 142 participated at the 2006-7 wave, the starting point for this secondary analysis (76% continuation), but of those, only 128 grandmothers were raising grandchildren in 2006-7. Subsequently, 125 of the original 183 grandmothers raising grandchildren participated in 2008-2009, but only 92 were still raising grandchildren at that time; and in 2014-2015, 41 of the 128 grandmothers in 2006-2007 participated, yielding a continuation rate of 32% from 2006-2007 to 2014-2015, which while indicating significant subject attrition is considered adequate for mailed surveys (Dillman, 2000) and nonetheless yields a unique longitudinal, qualitative data set. Thirty-five of the participants met study eligibility criteria and 20 were still raising grandchildren in 2014-2015.

Procedure

Institutional Board approval was obtained for this study. Grandmothers who had participated in three prior waves of the original longitudinal study (2001-2005) were notified by postal mail of two upcoming additional data collection points (2006-2007 and 2008-2009) that were supported by an NIH-funded continuation of the original study, and were re-consented; they were re-consented again for a sixth study wave in 2014-2015 when additional funding was obtained. Participants were contacted via telephone by staff to verify their caregiving status to grandchildren and were invited to participate in the next study waves. The study used mailed questionnaires that took about 25-35 minutes to complete. Participants were provided pre-stamped, pre-addressed return envelopes and an honorarium of $25 after returning questionnaires at each time point.

Measures

This qualitative study used a written questionnaire with open-ended questions to evaluate grandmothers' conflicts and concerns as related to grandmothers' family circumstances. This allowed grandmothers to describe their feelings and perceptions in detail.

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[1] At study onset in 2001, 183 grandmothers raising grandchildren participated, 159 participated 1 year after, 160 participated 2 to 2.5 years after baseline (2003), 128 participated 4 to 4.5 years after baseline (2006-2007), 100 participated 7-8 years after baseline (2008-2009), and 41 participated 13-14 years after baseline (2014-2015). Of the latter, 35 participants were raising grandchildren in wave 4 (which was the baseline and the inclusion criteria for this secondary analysis).

Family conflicts and concerns. To identify the family conflicts and concerns, grandmothers were asked: "In your family at this time, which are the greatest source of concern/worry?" and "In your family at this time, what is the greatest source of conflict?"

Family Circumstances. In the questionnaire, we asked grandmothers to describe their family circumstances at each time point: "In addition to you, who else lives in your household?," "Please, list all the people in your household and their relationship to you," "Do the parents of your grandchild(ren) live with you?," "Please, describe any changes to the living arrangements in your household" and "Do you help in the care of other people (family, friends, children)? If yes, please list them, their relationship to you, and how you help them." In 2006-2007, all grandmothers were raising grandchildren without parents in the home. At subsequent time points, grandmothers were categorized based on their family circumstances and responsibilities to grandchildren as follows: being a primary caregiver raising a grandchild, as a grandmother in a multigenerational home (grandmother, parent, grandchild) or as a non-caregiver to grandchildren living in a separate residence.

Demographic data. Age in years, race, marital status, job status, monthly income, level of education, number of grandchildren raised, and grandchildren's gender and age were collected.

Finally, there was an open ended item in which grandmothers were invited to write any additional comments.

Data analysis

The steps to analyze data were the following. First, based on the social ecological model (SEM) of health and behavior adaptation made by Shakya et al. (2012) to analyze concerns of grandparents in skipped generation families, the first author developed an initial version of the coding scheme beginning with 17 codes: (1) health, 2) financial difficulties, 3) grandchild academic achievement, 4) work issues, 5) family care, 6) death, 7) drug abuse, 8) house chores, 9) setting norms and limits, 10) troubled relationships with adult child, 11) prison, 12) grandchild future, 13) difficulties communicating with grandchild, 14) grandchild social relationships, 15) custody issues and visitations, 16) lack of adult support, 17) grandchild development.

The coding scheme was discussed with three other members of the research team. Then, two independent coders (the first author and a second coder) analyzed data through conventional content analysis, using a table of codes and their definitions. They followed the three abstractions levels stated by Corbin and Strauss (2014), in which relevant ideas were grouped into categories (open coding); then these categories were grouped into subcategories (axial coding); and finally, the categories and the subcategories were grouped into main categories (selective coding).

The two coders rated the transcriptions independently, then compared their coding, and reconciled coding discrepancies. Independent coding was performed in order to meet the four trustworthiness criteria (Guba & Lincoln, 2012): dependability, confirmability, transferability, and credibility. Data saturation was observed after analyzing the first 28 questionnaires, but analysis continued until all questionnaires were analyzed.

Cohen's kappa inter-coder reliability was analyzed using SPSS software and achieved inter-coder reliability of 0.92, which is considered almost perfect agreement (Cohen, 1960). For additional confirmation, the first researcher met with a third external expert in qualitative data

who suggested to group the 16 categories in five main categories: financial and emotional difficulties (codes 2, 4, 5, 16), grandchildren outcomes (codes, 12, 3, 13, 14), grandchildren mental health (codes 7, 9, 6), physical health (1, 8) and coping with visitations and custody issues (10, 11, 15). In addition, a new main category was created, faith, which was present in many responses and, although it was not a concern, it was an important factor that helped grandmothers to deal with these concerns and thus was included.

Finally, Cochran's Q tests were used to determine if there were differences on the six main categories developed over the three time points.

Results

Study Participants

Thirty-five grandmothers raising grandchildren participated in the three time points of this study: 2006-2007, 2008-2009, and 2014-2015. In 2006-2007, all grandmothers were primary caregivers raising grandchildren. At 2008-2009, 31 were primary caregivers (85%), two were living in a multigenerational home, and two were non-caregivers to grandchildren. Finally, in 2014-2015, 20 grandmothers were still raising grandchildren, 14 were no longer living with grandchildren, and one lived in a multigenerational home.

The main reasons why grandmothers continued to raise their grandchildren were parents' substance abuse (41.46%); parents' negligence or abandonment (24.39%); sexual abuse (7.32%); parents' mental issues (17.07%) or emotional immaturity (14.63%); and parents' incarceration (12.19%). Grandmothers' mean age in 2006-2007 was 58 years, 45.7% were married, and 57.14% were employed, with the 31.43% working part-time and 25.71% full time. In terms of educational level, 5.71% had less than high school education, 37.14% completed high school, and 57.14% studied beyond high school, with 14.28% having completed college. Grandmothers self-identified as White (68.5%), African-American (20%), or Multiracial (11.5%). More than 60% of grandmothers had monthly incomes <$3000. (Table 1).

Table 1
Demographics of Sample at 2006-2007 (N=35)

		2006-2007
Age	Mean (SD)	57.97 (7.37)
Marital Status	Married	16 (45.71)
	Not married with a partner	1 (2.86%)
	Widowed	8 (22.86%)
	Divorced	10 (28.57%)
Educational level	High school incomplete (9-11)	2 (5.71%)
	High school complete/GED (12)	13 (37.14%)
	Post high school, or trade school	5 (14.29%)
	1-3 years college	10 (28.57%)
	4 years college completed	3 (8.57%)
	Post gradúate college	2 (5.71%)
Paid work	No	15 (42.86%)
	Yes	20 (57.14%)

	Full-time work	9 (25.71%)
	Part-time work	11 (31.43%)
Monthly income		
	< 900	4 (11.43%)
	1000-2000	12 (34.29%)
	2001-3000	5 (14.29%)
	3001-4000	3 (8.57%)
	4001-5000	2 (5.71%)
	>5000	6 (17.14%)
Race	White	24 (68.5%)
	African American	7 (20%)
	Multiracial	4 (11.5%)
Grandchildren in care	Age (mean)	12.74 (SD=3.71)
	Females	27 (49.1)
	Males	28 (50.9%)

There were demographic changes over the three time points in marital status, work status, and number of children raised. By 2014-2015, two grandmothers remarried and five became widows. In addition, the number of children who were being raised decreased over time, with 55 grandchildren in 2006-2007, 48 in 2008-2009 and 29 in 2014-2015. Grandchildren's mean age was 12.74 in 2006-2007, 14.15 in 2008-2009, and 17.34 in 2014-2015. The proportion of males and females raised by grandmothers in 2006-2007 was similar, with 50.9% males, and no differences among the three time points.

We should mention that the sample of 35 had more education (t = -.71; p<.01), fewer problems in family functioning (t =.25; p<.05), and better health-related quality of life at baseline (t = .39; p<.01), compared with the other grandmothers who were raising grandchildren in the original study. In contrast, no difference in participants´ age, stress levels, intrafamily strain, and depression symptoms was found (for more information regarding the scales used to assess these variables, see Musil et al., 2006, 2009).

Identified Themes
Six main themes emerged from grandmothers´ descriptions of their conflicts and concerns and their family circumstances: financial and emotional difficulties, grandchildren outcomes, grandchildren´s mental health problems, coping with custody issues and visitations, physical health, and faith (Table 2).

Table 2
Identified themes at 2006-2007, 2008-2009 and 2014-2015

Variable	2006-2007 N= 35	2008-2009 N= 35	2014-2015 N= 35	Cochran´s Q			
				T1-T2	T2-T3	T1-T3	T1-T2-T3
Financial - Emotional Difficulties	22 (62.90%)	20 (57.10%)	13 (37.10%)	2.50	2.88*	5.40**	5.58*
Grandchild Outcomes	14 (40.00%)	11 (31.40%)	10 (28.60%)	.47	.09	.89	1.08
Grandchildren Mental Health	13 (37.10%)	13 (37.10%)	11 (31.40%)	.00	.33	.22	3.81
Custody and Visitation	7 (20.00%)	8 (22.90%)	2 (5.70%)	.91	4.5**	2.78	4.42*
Physical Health	11 (31.40%)	13 (37.10%)	11 (31.4%)	.33	.27	.00	.40
Faith	6 (17.14%)	7 (20.00%)	8 (22.90%)	.33	.20	2.00	1.20

*p<10; *p<0.05

Financial and Emotional Difficulties. Grandmothers identified financial and emotional difficulties as their main concerns at the first wave (2006-2007). Grandmothers stated that retirement was the expected transition according to their age and associated it to a series of contextual changes, such as a decrease in their financial status and social resources. Thus, this transition was associated to other changes, like health decline and the loss of the partner because of widowhood or divorce.

In contrast, having to take the responsibility for the care and education of a grandchild or support financially the parents of these grandchildren implied facing a series of unexpected financial and emotional costs that hinder grandmothers´ transition to retirement. In fact, some grandmothers reported they had to return to work after retiring or delayed their retirement in order to handle the new financial costs of grandchildren's care. During this period, two grandmothers moved into a house with a lower rent, one lost her house and another one stopped paying her and her husband's health insurance. As a result, negative perceptions were observed in which grandmothers stressed they were experiencing transitions "off time" when comparing with other people of their age and the isolation they feel because of the invisibility of their situation to their peers. One grandmother stated:

> *When I think of my education, social services knowledge, and financial and physical wellness, I can't imagine how so many grandparents survive the experience of raising grandchildren. It is an isolating and daunting task with tenuous and often disappointing results. The rewards are invisible to most of our peers who aren't likewise involved.*

During these eight years, there were other unexpected changes in the family circumstances, such as additional family members moving into the grandmothers' homes after losing their jobs, having health problems or divorce. Grandmothers expressed high levels of enjoyment and increased social support when other family members moved into their homes (son, daughters, grandchildren, or great grandchildren), particularly when their great grandchild moved in and they were not the primary caregivers. In contrast, two grandmothers, who had to take care over as primary caregivers to a new grandchild, described this situation as overwhelming and stressful. They felt as if they could not raise this new grandchild as they did with the other grandchildren they cared for in the past, due to the grandmother's health problems and less patience and energy.

Participants preferred developing a grandmother role over a parenting one. Specifically, more than 60% of grandmothers stated they were worried about not having enough knowledge about how to care for and support a child who had been exposed to traumatic situations (e.g., negligence or sexual abuse) and who they perceived as needing more emotional support. Particularly when grandmothers were just taking on the parenting role, they expressed feelings of anger and frustration due to lack of formal support to help them face this unexpected transition. Many wondered why foster parents receive financial support while they do not. In addition, many grandmothers complained about not having any financial or emotional support from their adult children to raise their grandchildren appropriately. For example, one grandmother stated:

> *Grandmothers' raising grandchildren need more financial assistance and social support to help any in rearing these children. Should be given the same support as foster mothers or foster parents who adopt children.*

However, these complaints decreased slightly over time, significantly among the second and the third wave, and nearly significantly between the first and the third wave. The decrease of grandmothers´ worries coincided with the grandchildren's greater independence when they left home and when their adult children improved their situation. In fact, some grandmothers reported that their adult children remarried and were raising new children, and two parents regained custody of their children after drug treatment. By contrast, relapse to substance abuse, incarceration and separation or divorce were factors related to greater concerns about their adult children's welfare. It is noteworthy that one daughter committed suicide.

Grandchildren Outcomes. In the first wave, grandmothers were very concerned about their grandchildren's future due to the uncertainty of who would take care of them and how the separation from the biological parents may affect them. Grandmothers expressed specific concern with challenges associated to grandchildren´s adolescence, such as grandchildren not respecting limits and social norms, academic achievement, social relationships, and difficulties communicating with them. For example, one grandmother explained how this affects her:

> *I just get stressed when I can't communicate with my granddaughter. She says I'm too old-fashioned (...). I know we'll get through this, but teens today have a different mindset from what I have ever experienced.*

Grandmothers described the relationship with their teen grandchildren as a challenge because they belong to a different generation educated in a different mindset. They perceived

this generational jump was greater than when they were mothers with added feelings of not having the same energy and patience to deal with these situations compared to when they were parents. When grandchildren living in the grandmothers' home showed oppositional behaviors, grandmothers perceived their living situation more negatively; especially when they felt they could not handle teen behavior problems or did not have enough financial or emotional resources. However, most grandmothers described these concerns as something temporary that would last until their teen grandchildren become adults, and many of them perceived these situations as a second chance to repair the mistakes made when they were parents.

In line with grandmothers expectations, these concerns were higher in the first wave (but not showing significant differences), when grandchildren were younger and showed limit-testing behaviors, such as arriving home late, talking back, not wanting to do homework, and displaying oppositional behavior, or even more disruptive behaviors such as stealing, dropping out of school, or substance abuse. When commenting on these changes, grandmothers reported ambivalent feelings, such as sadness and reward. The grandmothers' perceptions of reward in the caregiving role were higher when changes over time were related to grandchildren's positive outcomes (having a positive outlook for the future), such as grandchildren starting college or becoming independent with their own family or jobs (n=24). Also, six grandchildren moved back with their biological parents after the parent completed drug treatment or stabilized their employment situation. In these situations, grandmothers expressed they liked to have more time for themselves and their husband, if present. However, when grandchildren's motives for leaving grandmothers' home were related to high levels of family conflict (such as mental issues, substance abuse, or behavior problems), grandmothers reported feelings of frustration and relief. Nevertheless, there was a higher percentage of grandchildren who had positive outcomes.

Grandchildren´s Mental Health Problems. Grandmothers whose grandchildren had mental health problems, such as hyperactivity (13 grandchildren), bipolar disorder (seven grandchildren), depression (four grandchildren), and substance abuse (n=3) were more likely to report communication and socio-behavioral problems with their grandchildren. When interactions with a grandchild were perceived as "more difficult," the written comments of some grandmothers reflected a fear that the grandchild could develop mental, legal, or substance abuse problems similar to those of their parents. One grandmother stated:

> *Grandson's mother has an alcohol problem. She is now forced to go to counseling by court order. We are worried long term. He seems to be a lot like his mom.*

Some grandmothers were exposed to overwhelming situations that were difficult to manage. One grandmother expressed her concern for a grandchild who was neglected by his mother and sexually abused:

> *He is having difficulty expressing feelings. He is 13 years old and he might have been sexually abused. He's been hurting himself and he was playing [with] matches in this room.*

Six years later, this grandmother had to separate the two grandchildren she was raising and this grandson moved with his biological mother:

The oldest grandson has become abusive with his brother and it's a worry;
we sent him to the Juvenile Detention.

Another grandmother explained, in 2006-2007, how overwhelming it was for her to cope with her grandchild's emotional problems, her ambivalent feelings toward the situation and disagreements with her husband about how to help their grandson:

I feel very bad about [grandson's name]. I really love him, but I'm
overwhelmed with all the care he needs. I'm really sorry he tried to kill
himself, but I'm hoping to get more help for him now. I don't feel equipped to
handle him, but my husband doesn't want to "give him up to foster care," but
I don't know if I can take care of him anymore.

In 2014, after her husband's death, this grandmother sent this grandchild to foster care because she could not handle the situation any more, underscoring the importance of the grandfather's role as a support to custodial grandmothers. Several grandmothers stated that they would not be able to help their family if their husband had not supported them.

These two examples show how grandmothers in the first wave expressed important worries related to their grandchildren´s emotional problems and how, after several years, their worries were confirmed and were still present. In fact, there were no differences in this concern over the three time points, and some grandmothers in this study seemed to detect years in advance which grandchildren were at a higher risk of suffering from chronic mental health problems.

Physical Health. Grandmothers also showed concerns, that did not change over time, about the *physical health* of other family members, such as their grandchildren's parents, husband, parents, and even a brother. Many grandmothers were not only taking care of at least one grandchild, but also were taking care of other relatives who moved into their homes.

Although grandmothers expressed concerns about the health of other family members, very few grandmothers reported their own health as one of their main concerns (n=3). In fact, it is striking that no grandmother in 2014-2015 expressed concerns about her health, when one would expect increased concerns associated with the natural aging process. In contrast, those grandmothers who said they were concerned about their health in 2006-2007 and 2008-2009 were grandmothers with younger grandchildren who were worried about their health worsening or about what would happen with their grandchildren if they passed away. Specifically, these three grandmothers had some physical problems in time 1 (two had obesity and diabetes, and the third one had just suffered from a knee surgery) that made them difficult to perform the care tasks. In 2014, these grandmothers reported feeling better. For example, one grandmother in time 1 reported having obesity and diabetes, but in time 2 said she lost weight and was happy because of feeling lighter and being able to perform more tasks. In 2014-2015, the grandchildren of these three grandmothers were over 21, and grandmothers did not mention their own health as a concern. Relatedly, some primary grandmothers emphasized that caring for their grandchildren gave them a purpose of life and motivated them to continue living.

Although grandmothers did not directly express their own health concerns, household chores was one topic they often mentioned that may be indirectly related to their health. This

concern decreased from 2006-2007 to 2008-2009, disappeared in 2008-2009, but increased again in 2014-2015. The reasons they cited chores as a concern were different in 2006-2007 and 2014-2015. In 2006-2007, grandmothers emphasized a desire that grandchildren contribute to housework as part of the standards of living in the same house. In contrast, grandmothers who expressed these concerns in 2014-2015 usually had health and mobility problems that did not let them carry out these tasks properly and, as a result, they needed help from their grandchildren or other family members to carry out these tasks. Further, some grandmother-grandchild's roles were reversed in 2014-2015, with the grandchild caring for the grandmother:

> *I cannot help others at all. I can't even stand up to cook meals or clean house.*
> *I need lots of help. Granddaughter comes to clean every week, heat frozen*
> *dinners, make coffee, etc.*

The data suggest that this reversal of roles was experienced by grandmothers with frustration and sadness after realizing they could no longer help and care for their family as they did in the past.

Coping with Visitations and Custody Issues. At the first and second waves, grandmothers were concerned about how to cope with custody issues and parents' visitations. In particular, frequent worries observed in the grandmothers' comments were the fear of losing their grandchildren and the possibility that their grandchildren may move back with their biological parents who, according to grandmothers' perceptions, were unable to raise their grandchildren properly. In fact, grandmothers' satisfaction with their situation increased when they were given legal custody or guardianship and decreased when grandchildren increased contacts or moved in with their biological parents. Many grandmothers reported having troubled relationships with their adult children in the first two waves, often related to disagreements in child-rearing practices, rivalry, and custody and visitation management. Also, conflicts between different generations were observed due to discrepancies about who should be recognized as mother: the grandmother or the biological mother. For example, one grandmother stated:

> *My main concern is my granddaughter's mother getting nasty with her for*
> *calling me "mom" and telling her she doesn't have to listen to me because I'm*
> *not her mom.*

These conflicts with grandmothers' adult children were higher when the adult children were substance abusers, and grandmothers were also worried about the future of these adult children. However, these concerns decreased as time advanced (significantly among waves 2 and 3, and nearly significant among the time points 1 and 3), when the family circumstances for the grandchild were established.

Faith. Finally, grandmothers indicated that an important source of coping with stressful family conflicts was faith. For example, one grandmother stated that "even as bad off as my husband is, we have managed our children and grandchildren. Our faith, our love for one another, our desires to be there for one another has kept us grounded, focused and hopeful. God is good!" Religious practices ("prayer makes me feel better") and religious community support ("church family has been strong and together") were described as important resources for

grandmothers. They stated that God was watching out for them and "always sends what we need." This coping resource did not change over time.

Discussion

This study explored the family circumstances, conflicts, and concerns of grandmothers raising grandchildren over three time points. A paucity of data remains about the experiences of grandmothers raising grandchildren over time, yielding a rather static view of their situation without a sense of trajectory. While aggregate data suggests that initiating grandchild caregiving is associated with stress and depressive symptoms that may decrease over time (Hughes, et al., 2007; Musil et al., 2011), there has been little contextual data to provide insight into the dynamics of these processes. Our project extends insights derived from other cross-sectional and longitudinal studies of short duration (Hayslip et al., 2014; Kelley et al., 2013; Sands & Goldberg-Glenn, 2000).

One of the noteworthy findings of this study is that 20 grandmothers were raising grandchildren and/or great grandchildren for over 15 years' time. While some of these were grandchildren who had been infants at study outset and were in their mid- to late teens in 2014-2015, others were new grandchildren and great grandchildren who had moved into the grandmothers' homes more recently. The caregiving career has been applied to caregivers to older adults, but it has application to grandmothers as caregivers to grandchildren, too (Gaugler & Teaster, 2006).

Most grandmothers experienced several transitions in their caregiving status and family circumstances over time, decreasing significantly the financial and emotional worries, as well as the custody and visitation ones. Regarding these changes, the grandmothers described having ambivalent feelings, even when the changes in the family circumstances were positive and their responsibilities decreased. On one hand, grandmothers reported greater concerns when they experienced unexpected difficulties, such as handling grandchildren's emotional/behavior problems or when grandchildren were unable to transition to an independent life. Patterson (2002) noted that non-normative and unexpected transitions are more likely to be perceived as a significant risk, while normative and predictable transitions are related to less concerns in the family context (George, 1993). Thus, non-normative transitions can elicit other risks that, in turn, may set the family in a higher risk status (Patterson, 2002). Specifically, grandmothers in this situation stated they felt overloaded and frustrated; perceived they had a lack of knowledge, energy, and patience to deal with their grandchildren's difficulties; and claimed grandmothers should be provided with more resources (financial and emotional) that, in turn, may help them support their grandchildren.

Some grandmothers who were providing primary care to their grandchildren also experienced positive family transitions over time, such as the reunion of grandchildren with their mothers and the launching of grandchildren to adulthood when grandchildren moved out of their grandmothers' homes to attend college, work, or care for their own families. From an adaptation perspective (Patterson, 2002), non-normative changes in the family circumstances, such as grandchildren moving in with the grandmother to be raised by her, may push the family to one of the extremes of adaptation, either increasing or decreasing its competence.

The Resiliency Model of Family Stress Adjustment and Adaptation (McCubbin, 1993) suggests that family strengths and coping resources protect the family from stressors and facilitate adaptation. In this regard, we were able to observe the accommodative coping strategies of accepting the situation and positive reevaluation when grandmothers reported satisfaction with

their living situations despite the adverse circumstances that may have prompted these family structures. Several grandmothers felt that raising their grandchildren was a second chance to repair the mistakes they made when caring for their adult children, and that their grandchildren increased their purpose in life and motivated them to continue living.

Furthermore, spiritual or religious coping strategies also played a significant role in helping grandmothers to manage the stresses of caregiving. In this regard, several authors have stated that when spirituality acts as a growth source, it helps to reorganize the personal aims and priorities, as well as to find a meaning in life in older women (Harrison, Kahn, & Hsu, 2004; López, Camilli, & Noriega, 2015), like the grandmothers of this study. In addition, social support was described as an important resource (for example, when they reported the role played by church community, husband, or other relatives´ support), which is a variable that has been supported by literature as a moderator of the effects of stress on caregivers. Along this line, Musil et al. (2009) found that perceived social support moderated the effects of stress and family strain in grandmothers' mental health, being especially useful when the family strain levels were very high. As a consequence, the development of positive coping resources while developing generative activities, such as raising a grandchild, can help grandmothers achieve new aims that facilitate adaptation processes and, in turn, may promote their successful aging (Villar, Celdrán, & Triadó, 2012).

Other concerns reported by the grandmothers included financial hardship and emotional difficulties, health of the grandchild and other family members, grandchild's outcomes and the management of visitations and custody issues. But the concerns reported by grandmothers evolved over time, reflecting developmental changes in their grandchildren and in the grandmothers. These results are similar to the ones found by Shakya et al. (2012). Contrary to our results, the qualitative study by Brown et al. (2000) did not note the financial difficulties as a concern, a finding those authors regarded as unexpected. However, since the normative transition of participants´ age was retirement, which is normally associated to a decrease in the person´s finances, it makes sense that having to assume new unexpected costs to raise a grandchild increased grandmothers' worries about their financial well-being.

In contrast, in the study by Brown and colleagues (2000), the greatest concerns expressed by the grandmothers were associated with the grandchildren's sexual behavior, potential use of substances, and risk for encountering violence. Our findings indicated that some grandmothers had a concern about substance abuse, and it is possible that concerns about sexual behavior or violence may have been expressed less overtly within the themes of disregard for societal norms, troubled relationships, and communication problems. There also are noteworthy differences between the two studies. Our study was longitudinal and with a smaller racial mix, predominantly White (68%) sample, whereas Brown and colleagues (2000) focused only on African American grandmothers in a cross-sectional sample obtained 15 years before our 2014-2015 data collection point. Nevertheless, there is a need to consider differences in sociodemographic characteristics in order to develop appropriate intervention programs.

Implications
The results of this study highlight the necessity to consider the changes in the family circumstances, as well as family conflicts and concerns experienced by families headed by grandmothers over time, especially when these changes are related to financial or emotional difficulties, physical or mental illness, grandchildren's difficulties accepting social norms, and coping with custody and visitation issues. If grandmothers can withstand the challenges of child-

rearing during their grandchildren's development (specially in their first years providing care), some of their fears, concerns, and conflicts may decrease over time as evidenced by our findings.

Additional resources (financial and social) and psychological interventions that improve psychological well-being, family communication ,and social support over the caregiving years would help grandmothers and their families manage family conflicts and, in turn, increase the likelihood of positive transitions over time. Special attention should be given to counseling programs regarding parenting practices, discipline, and child development, in order to increase grandmothers´ resources and prevent the appearance of behavior problems similar to the ones described in this study, especially when grandchildren achieve adolescence. Thus, clinical practitioners should include family conflicts and concerns and changes in their family circumstances in their assessments, since these may be related to stressful situations for which intervention may be needed. The consideration of grandmothers´ heterogeneity and their specific context will help the development of tailored interventions to address grandmothers´ different needs and concerns. Finally, our findings point to the need to consider the role of coping strategies in helping grandmothers to adapt and to adjust to non-normative transitions, paying special attention to the value of positive religious coping strategies for some grandmothers caring for their grandchildren. This is especially important during the first years of care, since grandmothers showed greater worries and concerns in this period.

Limitations and Future Research

Our study has some limitations that must be addressed. First, there was significant attrition between baseline for the original larger study (2001) and baseline for this secondary analysis (2006-2007) and Time 6 (2014-2015), which may introduce bias into our analysis and conclusions. For example, the 35 grandmothers of this study had a better health-related quality of life when compared with the other grandmothers who were raising grandchildren in the original study, and this fact may explain why participants did not show concerns for their own health. Nevertheless, the opportunity to follow prospectively the experience of 35 grandmothers raising grandchildren offers unique insights into the dynamic nature of grandmother caregiving to grandchildren, an area of research that has received little attention in the past. To our knowledge, our study is the first to qualitatively investigate grandmother caregivers' family circumstances and concerns spanning more than eight years.

Women of color comprised only 32% of our sample, whereas in many other studies women of color comprise the largest segment of the sample, which may create some limitations for generalizability of our findings. Furthermore, we note that the phrasing of the open-ended questions may have some limitations, such as not having the opportunity to clarify grandmothers´ responses and difficulties obtaining deep information from grandmothers who were uncomfortable writing more detailed responses or had a lower education level. Nevertheless, the anonymity related to this procedure facilitated some responses that may be difficult for grandmothers to express verbally. Thus, the wording of the open-ended questions may have inadvertently emphasized negative aspects. More positively worded questions should be considered for future research.

Finally, these intergenerational situations are very complex. The methodology used has probably narrowed the narratives about the grandmothers´ personal concerns related to these complex transitions through time. Since the Cochran's Q uses a Chi Square statistic with small sample sizes, it is not as sensitive to identifying differences in data.

Despite these limitations, we believe this qualitative study makes a unique contribution to the grandmother caregiving literature with insights into the family arrangements and relationships of grandmothers and grandchildren over multiple years. Future longitudinal research focused on the trajectory of these families would add to our understanding of their concerns and successes, as well as provide additional insights on how best to support them.

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Research Article

Caregiving in sub-Saharan Africa and Older, Female Caregivers in the Era of HIV/AIDS: A Namibian Perspective

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Abstract
The human immunodeficiency virus (HIV) and the acquired immune deficiency syndrome (AIDS) have created an unprecedented 'orphan crisis' in sub-Saharan Africa. They have had a devastating impact on elder caregivers. Over 60% of children affected by HIV/AIDS are being care for by aging, often impoverished, grandmothers (AVERT, 2015). Yet there is a dearth of empirical work on the devastating impact of this pandemic on grandmothers. This article offers an overview of the literature with respect to what is currently known about caregivers generally and, specifically, older caregivers of orphans and vulnerable children (OVC) in sub-Saharan Africa. It addresses emerging policy initiatives and service delivery strategies in Namibia. Finally, it offers suggestions for policy and practice.

Keywords: HIV/AIDS, Namibia, older caregivers, orphans and vulnerable children

Over the past several decades, the HIV/AIDS pandemic in sub-Saharan Africa has had a devastating impact on every segment of society. The pandemic has created rapid and dramatic changes in HIV/AIDS caregiving, especially amongst older women (Boon et al., 2009; Govender, Penning, George, & Quinlan, 2011; Kuo & Operario, 2011; Lekalakala-Mokgele, 2011; Njororai & Njororai, 2012). It has also created what the United Nations has termed an *orphan crisis* (United Nations Programme on HIV/AIDS [UNAIDS], 2014). Older women often find themselves in highly stressful caretaking roles for both their HIV-infected adult children and their AIDS-infected or affected grandchildren (Lightfoot & Kalomo, 2010). This is especially true in Namibia where an estimated 250,000 people are living with AIDS and about 96,000 children have been orphaned as a direct result of the AIDS crisis (Centers for Disease Control & Prevention, 2013).

According to the United Nations, an HIV/AIDS *orphan* is defined as a child who has lost one or both parents due to HIV/AIDS (AVERT, 2015). Current figures suggest that approximately 3.2 million children worldwide are living with HIV/AIDS (AVERT, 2015). Compounding the crisis is the staggering rise of HIV/AIDS mortality rates among young, parental-aged adults in sub-Sahran Africa. The precipitous rise of deaths among this group has

placed significant social, economic, and political strains on society in general. It also has had a staggering adverse impact on the older adult caregivers who are often thrust into significant caretaking roles (AVERT, 2015). The already precarious situation of older adult caregivers, especially in rural areas of sub-Saharan Africa, is further complicated by changing sociocultural and familial values and roles, and unfavorable macroeconomic environments (Ice, Zidron, & Juma, 2008; Nyambedha, Wandibba, & Aagaard-Hansen, 2003).

The current article will offer a brief overview of the literature with respect to what is currently known about caregiving of orphans and vulnerable children (OVC) in sub-Saharan Africa. It will then address policy initiatives and service delivery strategies in Namibia as a case example of current efforts in service delivery in the context of the HIV/AIDS orphan crisis. Finally, it will offer policy and practice implications.

Literature Review

The African Context of Caregiving

African family life is known for large, extended kinship groups which are more complex and nuanced than conventional Western ideas of the nuclear family (Kayongo-Male & Onyango, 1984). Ethnographers studying African families note that grandparents are important familial linchpins to extended kinship networks (Fortes, 1969; Kayongo-Male & Onyango, 1984). Grandparents are important sources of wisdom—imparting knowledge, passing on traditional rules and regulations, and serving as conflict mediators. Adult children, in turn, have a traditional obligation to provide support to their parents, grandparents, younger siblings, and children (Ncube et al., 1997). This expectation continues among many African peoples and is embedded in cultural norms and values. Communal proverbs often remind children of their parental and grandparent obligations. For example, the *Kwanyama* tribe in Namibia has a proverb: *Kahuhwena hadela nyoko, nyoko onale ekuhadela*—translated as "We have to help our parents/elders because they helped us."

Additionally, fosterage—raising a child or children by someone other than the child's biological mother and father—has been a common practice across many African countries (Kuyini, Alhassan, Tollerud, Weld, & Haruna, 2009). Traditionally, children are viewed as precious gifts from God and the entire clan has a responsibility for their care. Children are often given to extended family members or other relatives not just for physical and social support but, for all intents and purposes, to become a part of that family (Isiugo-Abanihe, 1985).

HIV/AIDS Caregiving in Southern Africa

Southern Africa remains the region most severely affected by HIV/AIDS (USAIDS, 2012). This region has the highest rates of orphanhood in the world (AVERT, 2015; UNICEF, 2010). The devastating impact of AIDS-related morbidity and mortality is impacting many areas of southern African society. Some of these include family cohesiveness, food consumption patterns, and quality of care, as well as deepening poverty through hospital, medical, and funeral costs (Chimwaza & Watkins, 2004). The impact on older adult caregivers is also significant. According to Sefasi's (2010) Zambian study, 57% of primary caregivers are grandparents. Of these, 37% were between 60 and 85 years of age. A Botswanan study found that caregiving often prevented older adults from working full-time or earning their previous level of income (Heymann & Kidman, 2009). While researchers have long recognized the resilience of the African family (Ankrah, 1993), they also note that what was previously believed to be an

"impermeable traditional extended family network" (Miller, Gruskin, Subramanian, Rajaraman, & Heymann, 2006, p. 1430) is being eroded by the AIDS epidemic. These changing dynamics have placed a tremendous strain on all older adult caregivers and especially on grandmothers (AVERT, 2015).

Gendered Patterns of HIV/AIDS Caregiving

Recent research shows that older female caregivers shoulder enormous caregiving responsibilities for both ill family members and orphans (Hlabyago & Ogunbanjo, 2009; Njororai & Njororai, 2012; Ssengonzi, 2009). As early as 2000, the World Health Organization (WHO) found that older female caregivers cared for more than 80% of HIV-infected family members (WHO, 2000). In southern Africa, grandmothers provide the preponderance of care and support to their grandchildren affected by HIV/AIDS. Researchers have consistently shown that caregivers are more often than not adults aged 50 and older (Ardington et al., 2010; Kalomo & Liao, 2018), and living well below the poverty line (George, Govender, Bachoo, Penning, & Quinlan, 2014; Lindsey, Hirschfeld, Tlou, & Ncube, 2003; Shaibu, 2016). This gendered pattern of caregivng has been noted in studies conducted in Namibia (Kalomo, Kyoung, & Besthorn, 2017; Social Impact Assessment and Policy Analysis Corporation [SIAPAC], 2002), Botswana (Shaibu, 2016), South Africa (Lekalakala-Mokgele, 2011; Tshililo & Davhana-Maselesele, 2009), Uganda (Kamya & Poindexter, 2009), Togo (Moore, 2008), Kenya (Oburu & Palmerus, 2005), Tanzania, (Dayton & Ainsworth, 2004), Zimbabwe (Mhaka-Mutepfa, Mpofu, & Cumming, 2014b) and the Democratic Republic of Congo (Kipp, Matukala, Laing, & Jhangri, 2006).

Many orphans live with relatives before the biological parents die, and a grandmother is very often caring for several sets of orphans from different families at one time (AVERT, 2015; Desmond, Michael, & Gow, 2000; SIAPAC, 2002). These realities create "skip-generation parenting"—a result of a significantly reduced number of parental-aged adults able to support their children (Foster, 2000; Lightfoot & Kalomo, 2010). This skipped generation dynamic has altered the contours of caregiving arrangements. It significantly reduces the economic, social, and emotional stability of thousands of households headed by older, female adult caregivers (Njororai & Njororai, 2012) HIV/AIDS is changing the normal family trajectory of the middle generation traditionally expected to provide care to both young children and older adults. With the absence of a middle generation, grandparents do not have family members to care for them when they are aged and frail (Foster, 2000). Instead, the older adult parent, often the grandmother, is obliged to care for her dying child and is also left with the responsibility of later raising her orphaned grandchildren at a time when her own physical, cognitive, and emotional well-being may be at risk.

There is growing international concern for the caregiving role of AIDS-affected older adults (Stephen Lewis Foundation, 2015). A growing body of research has begun to examine the impact of HIV/AIDS on extended family networks and specifically on older adult caregivers (George et al., 2014; Kalomo & Liao, 2018; Mhaka-Mutepfa, Cumming, & Mpofu, 2014a; Shaibu, 2016). For example, goverments, especially in southern Africa, actively promote antiretroviral treatment (Government of the Republic of Namibia/Ministry of Health & Social Services [MoHSS], 2014; Madiba, 2012; Madiba & Mokwena, 2013) and support home-based programs (Pellizzoli, 2011). In brief, home-based care is defined as any form of care given to chronically ill people such as people living with AIDS in their home to promote, restore, and maintain an individual's livelihood and provide the best possible quality of life including care

toward dignified death (Pellizzoli, 2011). Despite government attempts to develop supportive initiatives for older adult caregivers, these efforts often remain underdeveloped and poorly coordinated (Kautz, Bendavid, Bhattacharya, & Miller, 2010; Schatz, Madhavan & Williams, 2011). Moreover, older adult caregivers often remain "invisible" (Chazan, 2008) with respect to the allocation of scarce resources and support. As Marais (2005) noted:

> While most of the attention is directed at the prospects of those in their care, little of note is being done to meet the material, emotional, and social needs of older adult caregivers and fosters--the "reverse orphans" who, in the twilight of their lives and grossly disadvantageous circumstances, are transforming themselves again into mothers and fathers (p. 82).

The High Toll of HIV/AIDS for Older Adult Caregivers

Research indicates that OVC thrive better and are more likely to have their needs met when in the care of kin caregivers (Haihambo, Hayden, Otaala, & Zimba, 2004). But, older caregivers are grappling with the increased demands of children in their care (Hayden & Otaala, 2005; Kalomo et al., 2017; Ruiz-Casares, Thombs, & Rousseau, 2009; SIAPAC, 2002). Scholars have found that African extended family support systems are struggling to provide adequate social, financial, and material support to older caregivers (George et al., 2014; Njororai & Njororai, 2012). Caring for orphaned children entails a range of responsibilities that amplify caregiving demands. Some of these include a lack of transportaion and financial resources to afford proper health care or provide nutritional food (Njororai & Njororai, 2012; Steintz, 1998). Other demands include increased household routines (Dayton & Ainsworth, 2004; Kalomo & Liao, 2018) while tending to their own medical and financial needs (Mhaka-Mutepfa et al., 2014a; Levine, Van der Berg, & Yu, 2009). Moreover, AIDS-infected and affected children have additional needs that also amplify caregiving demands. They are more likely to experience AIDS-related stigma and emotional problems in addition to the physical manifestation of their condition (Cluver & Gardner, 2007). Caregiving duties are creating complex challenges for older caregivers. Higher demands on household chores, impacts on emotional well-being (Kagotho & Ssewamala, 2012; Schatz & Gilbert, 2012), and increased physical illness (Mhaka-Mutepfa et al., 2014b; Schatz et al., 2011) are not uncommon.

The emotional well-being of older adult caregivers is also being compromised by their increased caregiving demands. A study of the experiences of caregivers losing an adult child to AIDS in Togo, West Africa found that women were bearing the heaviest emotional burden (Govender et al., 2011). They experience multiple vulnerabilities such as anxiety, depression, HIV-related stigma, PTSD, and untreated physical and psychological illnesses (Chazan & Whiteside, 2007; Kagotho & Ssewamala, 2012; Kalomo et al., 2017; Kiwanuka, Mulogo, & Haberer, 2014; Kuo, Reddy, Operario, Cluver, & Stein, 2013; Schatz, & Gilbert, 2012). Kuo, Fitzgerald, Operario, and Casale's (2012) South African study, examined the prevalence of depression in a sample of adults who were primary caregivers to orphaned children. The study found 30% of the participants reached the clinical threshold of depression regardless of whether they were caregivers of AIDS-orphaned children or children orphaned for other reasons. A Ugandan study focusing on the challenges faced by adult caregivers showed that caregivers reported experiences of significant emotional distress (Ssengonzi, 2009). Similarly, a Kenyan study, one of the few examining stress among the older adult caregivers of orphans found that caregivers reported high levels of emotional distress (Oburu & Palmerus, 2005).

Social and Financial Supports for Older Adult Caregivers

While stress on older adult caregivers has grown during the HIV/AIDS crisis, available supports to help manage increased demands are often insufficient (Lekalakla-Mokgele, 2011). Hlabyago and Ogunbanjo's (2009) study of caregivers of AIDS-orphaned children showed that caregivers reported a lack of social support services and support from extended family. Support denotes any form of assistance such as financial, material, or social used by caregivers to mediate caregiver responsibilities. An analysis of multiple studies addressing survival strategies employed by HIV/AIDS-affected households found that many older adult caregivers reported having to sell land and property or using their savings to support children in their care (Naidu & Harris, 2005). Thus, researchers have identified the importance of financial supports such as child maintenance grants, micro-lending loans to start income-generating projects (Nabunya, Ssewamala, & Ilic, 2014; Plagerson, Patel, Harpham, Kielmann, & Mathee, 2011). Kagotho and Ssewamala's (2012) Ugandan study examined factors associated with better emotional outcomes of older caregivers. They found that financial and social supports were correlated with caregivers' levels of depression. Other studies have shown similar results (Kuo, Fitzgerald, Operario, & Casale, 2012; Myint & Mash, 2008; Okawa et al., 2011). A Malawian study of older caregivers found that while 75% did received some form of financial assistance it was equivalent to only a meager $81 (U.S.dollars) annually (Kidman & Heymann, 2009).

Material supports such as food, clothing, blankets, school supplies, and medical assitance are also important (Schatz et al., 2011). The lack of accessible treatment options and affordable medication adds to the caregivers' financial burden (Mathambo & Gibbs, 2009). It is not uncommon for grandparents to depend primarily on their government-funded pensions. Due to high levels of poverty and unemployment, pensions are often the most stable and reliable income for many older adults (Kimuna & Makiwane, 2007). Unfortunately, data has shown that the older adult caregivers have no choice but to use large portions of their monthly pensions to supplement household income to buy food, clothing, and shelter; pay school fees; and provide transportation, as well as cover funeral costs and medical expenses when their adult child dies and leaves behind OVC (Ardington et al., 2010; Moore, 2008; Taukeni, 2011).

The current review suggested a number of factors impinging upon older adult caregivers raising children orphaned by HIV/AIDS in sub-Saharan Africa. First, evidence indicated that the HIV/AIDS pandemic has altered the contours of living arrangements and traditional roles among the African family and grandparents have generally stepped into the breach to become primary caregivers to AIDS-orphaned children. Second, the literature revealed a gendered pattern to caregiving with grandmothers becoming the primary and, in many cases, the sole provider of support for OVC. Third, the caregiving experience imposed a myraid of social, economic, emotional and physical challenges to older adult caregivers. And finally, the multiple problems that compound older adult caregiving may be attributed to the lack of caregiver supports, consequently pushing caregivers beyond their capacities to both care for themsleves and to care for AIDS-orphaned children. With the previous overview as contextual backdrop, we shall now look specifically at the Namibian experience in the era of HIV/AIDS.

Namibia's Orphan Care Response in the HIV/AIDS Era

The literature suggests that a number of countries in sub-Saharan Africa, such as South Africa, Zimbabwe, Botswana, Lesotho, and Swaziland, have been in the forefront of relief efforts to address the HIV/AIDS pandemic. However, a great deal is still unknown about efforts in other

areas of the continent. Namibia is a case in point. Only in recent years has a body of literature begun to emerge looking in greater detail at Namibia's response to this issue. Data shows that older adults, especially those 50 years and older, are primary caregivers for AIDS-orphans in Namibia (Centers for Disease Control & Prevention, 2013). An earlier study in Namibia also found that 56% of the primary caregivers of AIDS-orphans were grandmothers aged 60 years and older (Project Hope, 2006). The following overview will begin to shed light on this issue from a Namibian perspective.

Community-Based Support in Namibia

Namibia has a small diverse population of approximately 2.1 million inhabitants, with roughly 67% living in northern rural areas (Namibia Demographics Profile, 2013). The largest social and public health concern in Namibia is the HIV/AIDS pandemic. Recent estimates suggest that Namibia has 250,000 people living with HIV/AIDS and that about 96,000 children below the age of 18 have been orphaned as a direct result of the HIV/AIDS crisis (UNAIDS, 2014). About 18,000 children are infected with HIV/AIDS and one in 10 are living with at least one chronically ill older adult caregiver (UNAIDS, 2014). Many AIDS-orphaned children live in poverty with about 22% living with an older adult pensioner (Namibia Statistics Agency [NSA], 2012). International assessments have shown older adults, especially those 50 years of age and older, are primary caregivers for children orphaned by AIDS in Namibia (UNAIDS, 2014). Countrywide, the number of orphans cared for by older adults, especially grandmothers, have increased significantly (NSA, 2012; Lightfoot & Kalomo, 2010; UNAIDS, 2014).

The Namibian government advocates for community-based support rather than institutionalization to care for AIDS-orphaned children. The policy recognizes a strong cultural expectation that extended family and other community members care for OVC in the spirit of "*ubuntu*," an ancient African word meaning "humanity to other" and "I am what I am because of who we all are" (Nkosi & Daniels, 2007 p.18). Within this framework, love and care for the *other* is not constrained to blood relations but extended to the clan, neighborhood, village, or community. As such, in "*ubuntu*" cultural practice, families and local communities embrace each other and share a bond of reciprocal love for one another.

However, research has found that despite this strong cultural heritage, enormous gaps in orphan care still exist, especially if the responsibility rests solely on the shoulders of extended families and local communities (Government of the Republic of Namibia/Ministry of Gender Equality and Child Welfare [GRN/MGECW] 2008; UNAIDS, 2011). Data suggests this form of community support is often ill-equipped and overstretched, leaving caregivers struggling to provide quality care (UNAIDS, 2011). Thus, it is critical that extended families and local communities experiencing multiple losses, stigma, and discrimination associated with the HIV/AIDS crisis receive sufficient supports from governmental agencies, non-governmental organizations (NGOs), and the larger society.

Policies and Legislative Support in Namibia

The Namibian government has increased its efforts to develop policies and legislative initiatives for the care and support of OVC. While a number of these policies are works in progress, it is evident that the country is developing a positive legal framework to facilitate new policy agendas. For example, the Children's Act (1960), OVC Policy (2004), the Policy for Educationally Marginalized Children (2002), the Child Care and Protection Action and Children's Status Act, HIV and AIDS Policy for the Education Sector (2003), and the HIV/AIDS

Charter of Rights are examples of initiatives to help support the care of OVC. In addition, the Ministry of Education, Arts and Culture (MoEAC), responsible for school feeding programs; the Ministry of Home Affairs and Immigration (MHAI); and the Directorate for Civil Registration have also begun to address the OVC crisis (UNICEF, 2016). To date, however, Namibia does not have a strong policy agenda focusing on the unique needs of older caregivers.

As suggested, OVC policies currently in place are designed to promote family caregiving as the most stable and favorable setting for OVC children. These policies emphasize first-order principles such as the best interest of the child, the importance of strong local leadership and commitment, multisectoral approaches and partnerships, and the protection of human rights (GRN/MGECW, 2004). Although, policy initiatives and a legislatively supportive environment have evolved, data indicates that multiple barriers still hinder the effectiveness of service delivery for OVC and their older adult caregivers. One study found that older adult caregivers and many orphans could not access available welfare grants mainly due to a lack of official supporting documentation such as birth certificates, identification documents, and death certificates (Taukeni & Matshidiso, 2013). Similarly, studies have shown older adult caregivers were struggling to keep dependents in school—citing lack of money for school fees and school uniforms (GRN/MGECW, 2012; Mnubi-Mchombu & Ocholla, 2011; Taukeni, 2011). In addition, problems exist with respect to the need of legislation to protect the inheritance and property rights of orphans and to seasonally adjust welfare grants based on inflation rates (GRN/MGECW, 2012).

Governmental Support in Namibia

In Namibia, the three governmental organizations provide much of the country's social welfare. They are the Ministry of Health and Social Services (MoHSS), the Ministry of Gender Equality and Child Welfare (MGECW), and the Ministry of Labour and Social Welfare (MoLSW). According to UNAIDS (2011), the total number of social welfare grants in Namibia rose from 86,550 in 2007 to 118,089 in 2010—a significant increase largely due to the social consequences of the HIV/AIDS crisis (GRN/MGECW, 2012; Taukeni, 2011). As of March 2016, the total number OVC benefiting from the grant system was 285,431 (UNICEF, 2016).

The Ministry of Labour and Social Welfare provides a monthly N$450 (US$58.44) old-age pension to adults aged 60 years and older. The MoHSS focuses on adult's health and social care needs, while the MGECW focuses on children (UNAIDS, 2011). As a coordinating body, the MGECW is tasked with ensuring the protection, care, and support of OVC. Their charge is to afford OVC access to available services while being responsible for implementing and monitoring Namibia's National Plan of Action for Orphans and Vulnerable Children (NPA 2006-2010). MGECW also provides maintenance and foster care grants and place-of-safety allowances for families caring for OVC (GRN/MGECW, 2012).

Clearly, the Namibian government is committed to assisting OVC and their families. However, challenges have been identified that impede the smooth functioning of service delivery. These issues include insufficient number of qualified social workers, limited supervision, lack of transportation, inadequate office space and resources, burnout, and insufficient data on service provision and client outcomes (Chiwara & Lombard, 2017; Taukeni, 2011; UNAIDS, 2011). The government's efforts are further impaired by cumbersome processes associated with administering welfare grants. These inefficient processes minimize the ability of social workers and other service providers to perform their core function, such as providing counseling and psychosocial support, conducting home visits, and monitoring children's

development and their conditions of safety. Data suggests that supports from governmental agencies are often limited to brief counseling, grants and allowances, and health care services with much of the casework load of service providers focused on administrative tasks rather than direct services (Chiwara & Lombard, 2017). This contrasts with service delivery priorities of NGOs, which tend to be focused on day-to-day needs of OVC caregivers (Chiwara & Lombard, 2017).

International and National NGO Support in Namibia

Namibia has several international and national non-governmental organizations (NGOs) complementing the government's efforts to provide support to caregivers and their OVC dependents. These efforts include feeding programs; provisions of vouchers for school uniforms; educational, material, and nutritional support; and income-generating activities (UNAIDS, 2011). Additionally, Namibian churches and faith-based organizations have organized themselves into the Church Alliance for Orphans. For example, Catholic AIDS Action's (CAA) core commitment is to a combination of home-based services coupled with educational and psychosocial care for OVC. The Katutura Youth Enterprise Centre provides vocational training to both OVC and caregivers. The Namibian Red Cross Society offers material support, and Project Hope focuses on microfinancing for caregivers (UNAIDS, 2011).

Unfortunately, studies assessing the impact of NGO service provision to OVC and their caregivers found that the majority of service organizations in Namibia were unable to meet the support needs of OVC and their caregivers (Boston University Pharm Access Foundation, 2009; Taukeni, 2011). Similarly, studies of supports in the Ohangwena and Omusati region of rural northern Namibia found that many services targeting OVC and their caregivers were located in urban areas. This makes accessibility a real challenge to hundreds of caregivers in rural areas, the majority of whom have scarce financial resources and lack transportation (Kalomo et al., 2017; Taukeni, 2011; Nekundi, 2007).

Implications for Policy and Practice

The impact of HIV/AIDS on familes in southern Africa is profound and ongoing. The previous discussion reviewed the scope of the current crisis in sub-Saharan Africa, as well as policy and service delivery initiatives in Namibia. Some strides have been made in policy regarding protections for vulnerable populations (GRN/MGECW, 2012). However, an important missing piece is the lack of a comprehensive understanding of and services for one of the most critical components of the OVC continuum—older female caregivers. Given that grandmothers play a critical role in providing care to Namibia's 250,000 OVC (UNAIDS, 2011), a more detailed understanding of these vulnerable caregivers' needs can help inform the development of culturally appropriate micro, mezzo and macro level interventions. Policymakers need to prioritize strategies to address the physical and psychosocial needs of older, female caregivers in high HIV-prevalence settings and socioeconomically deprived communities, especially in rural areas in Namibia.

Therefore, we argue for more comprehensive policies and interventions that help strengthen the physical and emotional wellbeing of older, female caregivers. These need to be sustainable over the long term and must focus on both macro economic/financial initiatives as well as micro and mezzo psychosocial supports. They need to be designed in such a manner as to support the inherent resilience of African families by focusing on external vulnerabilities and psychosocial stressors threatening household viability (Drimie & Casale, 2009). As an example,

one of the most pressing macro level needs of HIV/AIDS-affected households is the problem of food security. Many older adult caregivers lack sufficient financial supports to provide the needed nutrition for children in their care. Additionally, researchers have found that the majority of older adult caregivers are often too physically weak to engage in active food production (Government of the Republic of Namibia/National Planning Commission [GRN/NPC], 2012; Nhongo, 2004; Smith, 2007). Therefore, the Namibian government, NGOs, and civic/faith-based organizations must critically focus on increasing food security in households headed by older adults, particularly those raising OVC. Alleviating food insecurity in HIV/AIDS-affected households will go a long way toward decreasing the psychosocial distress of these vulnerable caregivers.

This review evidences a compelling need for stakeholders in Namibia to put in place a comprehensive older adult caregiver policy. Such policies should, at the very least, address macro level antipoverty strategies and sustainable economic opportunities. Community-based capital cash transfers (Skovdal, Mwasiaji, Webale, & Tomkins, 2011), child support grants, of and youth saving accounts (Ssewamala, Neilands, Waldfogel, & Ismayilova, 2012) are viable examples. Other initiatives might include providing easier access to social welfare grants, offering free or low cost family counseling, establishing community food gardens, and providing other in-kind support assistance targeted to the unique needs of individual communities and families.

Policymakers, social workers, and other helping professionals must also give more sustained attention to the mental health needs of older adult caregivers. A need presents to prioritize and invest in evidence-based research, assessment, and interventions that address the mental health needs of those living in resource-limited and HIV/AIDS affected communities. These approaches might include targeted therapeutic interventions specifically designed for older adult caregivers and those children in their care (Kagotho & Ssewamala, 2012). The literature is clear that targeted mental health services targeted to older adult caregivers can be efficacious and cost-effective (Boon et al., 2009; Kagotho & Ssewamala, 2012; Kuo et al., 2013; Kuo & Operario, 2011).

Additionally, practitioners must be trained and experienced at providing   psycho-educational and/or support groups aimed at teaching caregivers ongoing coping skills to better adapt to their demanding caregiving responsibilities. Coping assessment and traning has been shown to be efficacious in many settings (Chesney, Folkman, & Chambers, 1996). Developing culturally sensitive coping interventions tailored to the African context holds much promise in buffering the effects of caregiving responsibilities. In addition, targeted age-sensitive and gender-specific preventative measures, such as HIV/AIDS educational campaigns, would go a long way toward increasing caregivers' knowledge of how to eliminate further HIV transmissions.

Finally, macro level public awareness campaigns and enforcement efforts are needed in order to help modify the social climate related to the HIV/AIDS crisis. The Namibian government together with other stakeholders should strengthen enforcement of HIV-related anti-discrimination policies and laws. Additionally, more concerted efforts are needed to develop more gender perspective interventions in community-based care and support. This endeavor might include programs to increase the role of men and boys in caregiving responsibilities beyond what has been their traditional role.

Conclusion

This paper has reviewed literature addressing the impact of the HIV/AIDS crisis in sub-Saharan Africa. It has addressed caregivers raising children orphaned by HIV/AIDS. And specifically, it has found that orphan caregiving is undertaken primarily by older adult women. Not surprisingly, this caregiving is largely done amidst multiple social, economic, and physical challenges. The current trajectory of service delivery in Namibia was specifically examined, with the recognition that gaps exists in policy and intervention stategies for older adult caregivers. An urgent need is indicated for a much broader public and private partnership to help buffer the myriad of challenges that older adult caregivers face. Undoubtedly, this finding also suggests a compelling need for social work professionals, researchers, program planners, policymakers, national governments, and NGOs to develop and fund greater levels of empirical research to gain a more detailed and nuanced understanding of this growing crisis. In addition, assistance is critically necessary to educate, train, and raise awareness among older adult caregivers about accessing welfare grants for children in their care, which currently are available but are under-utilized due to complexities of the application process (Govender et al., 2011; Taukeni, 2011).

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Research Article

Grandparent Caregivers' Perceptions and Lived Experiences: Their Health, Access to Health, and the State of Health Services in Zimbabwe

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Abstract

The study explored the perceptions and lived experiences of self-rated health, access to health, and state of health services for grandparent caregivers in Zimbabwe. In–depth interviews using semi-structured interview guides were carried out to elicit perceptions of lived experiences from grandparent caregivers (N=31; Mean age= 65.7; SD= 10.7). The data was thematically analysed and the software Nvivo 10 was used to help categorize emergent themes. The study found that grandparent caregivers experienced multiple chronic and complex self-rated health conditions (e.g., High blood pressure (HBP), arthritis, diabetes, hypertension, back pain, and heart problems), which influenced their health and Quality of Life (QOL). They perceived health services as inaccessible without medical insurance and provision of health services in Zimbabwe as appalling and prohibitive, particularly in rural areas. The negative perceptions of health services impacted caregivers' willingness to seek the services when needed. Some of the caregivers resorted to traditional healers and religious leaders' services as alternatives to conventional health services for coping with poor physical and mental health. The high prevalence of self-reported chronic illnesses and the crisis in the health sector was lamented by most grandparent caregivers, indicating the need for access to quality health care and/or services, medical insurance, and social protection services.

The majority of older caregivers in sub-Saharan Africa, particularly in Zimbabwe, are poverty-stricken, food insecure, and lack access to health and social services (M Mhaka-Mutepfa, E. Mpofu, & R Cumming, 2015). Few African countries have provision of security grants or formal systems for caring for older persons and most of the elderly rely on traditional family structures. Migration, modernization, and urbanization have also diminished kin support for older persons (UN, 2016). Becoming a grandparent carer adds a layer of complexity and is typically not easy nor always voluntary as it affects health and well-being, particularly during the AIDS era that has hit sub-Saharan African countries harder than any other area (M. Mhaka-Mutepfa, E. Mpofu, & R. Cumming, 2015). The HIV and AIDS pandemic has shifted the role of grandparents from secondary caregivers of their grandchildren to primary caregivers for orphaned grandchildren.

In addition, in countries with a high prevalence of HIV/AIDS, many households are increasingly headed by the elderly leading to increased vulnerability to poverty

(Aboderin & Beard, 2014). The elderly caregivers are likely to experience chronic health conditions, physical degeneration, and frailty as a result of the aging process, which is exacerbated by caregiving. Previous studies attest to the risks caregiving poses to health (e.g., stress and depression) (Hayslip & Smith, 2013), long term changes in stress responses (Kidman & Thurman, 2014; Oburu & Palmérus, 2003), and an increased risk of infectious diseases (Aboderin & Beard, 2014). Women in many, if not all cultures, carry a disproportionate burden of household responsibilities and activities, a burden that may also pose a threat for progressive illness (Magen Mhaka-Mutepfa, Cumming, & Mpofu, 2014). Illness requires accessibility to health services which are well monitored and managed, not the case in low income countries.

Previous studies reported that lack of access to health services, poor state of primary health care facilities, and lack of human and material resources were associated with poor health and well-being, thus caregivers may fail to cope with caregiving roles (Cheng, Linda, & Kwok, 2013; Mugisha, 2013; Sayegh & Knight, 2011). The way people perceive their self-rated health and availability of health services has an impact on their subjective well-being. A carer who perceives his/her health as very bad and the state of health services as poor because of lack of resources (medication, personnel, water, etc) is not likely to seek medical treatment (McKoy-Davis et al., 2017). This decision further aggravates their health and well-being. For instance, Newsday Zimbabwe reported that the Zimbabwe government has relied on inadequate and irregular donor support (e.g., NGOs like UNICEF: United Nations Children's Fund) to run the public health systems (The-Editor, 2015). As a result, the government has failed to provide adequate health services to its people, especially the 90% of the population without medical insurance (Newsday, 2015), despite making empty promises.

Further, 90% of the population in Zimbabwe are not formally employed and are living below the poverty datum line; therefore, they cannot afford medical insurance (Mhaka-Mutepfa et al., 2015). However, beneficiaries of the public health system are not required to pay to access services, but drugs are hardly available in the public health facilities so patients have to buy from private pharmacies. The patients also have to commute, particularly those residing in rural areas, as pharmacies are located in urban areas. In addition, long queues and poor quality of service are common (Dhemba & Dhemba, 2015). The state of the health services and services rendered thus affect caregivers' perceptions, well-being, and their health-seeking behavior.

The paper (Newsday) also revealed a huge crisis in the health sector. For instance, in 2015, the government allocated 301 million USD to the health sector for a country of 13.5 million people, suggesting that on average each person was allocated 22 USD that year. Other sub-Saharan countries allocated much more, for example, South Africa allocated 650 USD per person, Botswana 390 USD per person, and Angola 200 USD per person. Furthermore, there are 1.6 doctors per 10,000 people and seven nurses per 10,000 people in Zimbabwe. The country also has shortage of specialists: four neurosurgeons, two heart surgeons, three dermatologists, and one venereologist, according to data in Zanu PF's 2013 election manifesto (Newsday, 2015). Zanu PF (Zimbabwe African National Union –- Patriotic Front) has been the ruling party in Zimbabwe since independence from British colonial rule in 1980 and is still the ruling party. Health services have deteriorated during their empowerment because of corruption and mismanagement of resources.

Failure to Seek Health Services Because of Stigma
Previous researchers in Zimbabwe reported positive perceptions of aged persons, with a few viewing the aged as "witches or wizards" (Kazeze, 2008; Ssengonzi, 2009).

The strong sense of community, interdependence, and connectedness that existed in sub-Saharan Africa before the AIDS era has been eroded. Caregivers may feel ridiculed, unvalued, and disrespected because they are fostering HIV-infected orphans. The negative feelings and abuse may reduce caregivers health-seeking behaviors for fear of ridicule. The abuses (stigma and discrimination) of old persons were also found to be within the households and communities in Tanzania and South Africa and were hardly reported (Helpage-International, 2008; Kazeze, 2008; Ogunmefun, Gilbert, & Schatz, 2011). Stigma and discrimination may lead to social isolation and emotional distress among caregivers, thereby affecting their self-rated health status, self-reported symptoms, and well-being. Stigmatized caregivers may not seek health services lest they are stigmatized.

Studies in sub-Saharan Africa reported that stigma and discrimination were rampant and were perpetrated by professionals, particularly health personnel (AVERT, 2016). The People Living with HIV Stigma Index indicates that roughly one in every eight people living with HIV is being denied health services because of stigma and discrimination (UNAIDS, 2015). If caregivers are stigmatized by health personnel, seeking medical care for themselves and their grandchildren becomes a hurdle. Social exclusion and marginalization are major challenges facing older persons (Tran, Ohinmaa, & Nguyen, 2012), particularly caregivers of orphaned children. Information on stigma and prejudice is vital for the private and public sectors to formulate policies that enable caregivers and their grandchildren to access health services.

However, previous research has documented the benefits of caregiving to grandparent caregivers with personal and social resources (Fruhauf & Bundy-Faziolli, 2013; Hayslip & Smith, 2013; M. Mhaka-Mutepfa et al., 2015). The resources enable the caregivers to seek health services and therefore cope with caregiving. Further, perceptions of accessibility to health services and the state of health services are important to grandparent caregivers as they enhance their ability to manage their health by seeking services.

The Situation in Sub-Saharan Africa

Approximately 50-60% of people living with HIV in sub-Saharan Africa are being cared for by an older person, with each older carer looking after an average of two people affected by HIV (United Nations, 2016). Studies in Lesotho and Namibia have revealed that the elderly spend up to 70% of their money on other people, mainly young children (Guven & Leite, 2016). Some older people are sexually active and are also infected with HIV, and this state affects their health and carer roles (Kidman & Thurman, 2014), hence they need access to health services. In Botswana, 21% of people in their early 50s are HIV-positive, compared to 25% aged 15-49 years (Ama, Dwivedi, Shaibu, & Burnette, 2015). Poor health among the older people with carer responsibilities may impede their caregiving roles because they may worry about their own health. In many cases, the orphans are being looked after by their ailing grandparents, who also have needs of their own, exacerbating work overload and the poor health (Mhaka-Mutepfa et al., 2014).

In sub-Saharan African countries, financial strain and poor health were found to be a major problem among grandparent caregiver families, where grandparents are overwhelmed and children fare poorly (Matshalaga, 2004; Nyasani, Sterberg, & Smith, 2009). In addition, old age is often accompanied by a reduced capacity of income generation, senility, and a growing risk of chronic illness. Poverty in Zimbabwe is estimated to be over 70% and the rate of unemployment is estimated to be over 85%

(Newsday, 2015). These figures suggest that Zimbabwe has other urgent and pressing issues to resolve beyond the health of aging caregivers.

Caregivers' narratives of their perceptions and lived experiences of the health services should be captured to provide alternative and self-reported perspectives other than those of healthcare providers (Jones et al., 2016). The lived experiences of grandparent caregivers should be explored to enable stakeholders to formulate suggestions for resolving issues for the growing elderly population. Most of the elderly need access to health services since the disability adjusted life years (DALYS) are increasing (Aboderin & Beard, 2014). Life expectancy will have risen to 83 in developed countries and 74 in developing countries by 2050. The demographic transition is not supported by policies that address poverty, ill-health, and the state of health services in African countries, let alone Zimbabwe. The increase in numbers of older people is proportional to the burden of providing social services, particularly healthcare services which may affect the caregivers' health-seeking behaviors, therefore impacting their health and wellbeing (Tran et al., 2012).

Data on the impact of perceptions of livelihood strategies, self-rated health status, and state of health services for older people in Zimbabwe is unavailable, making tailored intervention difficult. The Zimbabwe government has enacted the Older Persons Act of 2012, which has not been implemented due to lack of funding (Dhemba & Dhemba, 2015). Without support services to grandparent caregivers, accumulated interpersonal losses (e.g. loss of a spouse, children, familiar environment, job income, physical health, and negative perceptions of health services) threaten the fulfilment of their daily living needs and life satisfaction (Tran et al., 2012). Other problems encountered by grandparent caregivers include age and gender discrimination, lack of access to health services, lower earning capacity, and limited access to land ownership.

This paper is part of a larger study that explored the perceptions and lived experiences of grandparent caregivers fostering grandchildren in Zimbabwe. The article explores caregivers' lived experiences and perceptions of their self-rated health, access to and state of health services in grandparent communities, and the stigma that affect their health-seeking behaviors. Self-rated health is an important aspect of self-perceived well-being (Taylor, 2013). A qualitative study of grandparent caregivers is therefore crucial for highlighting issues that need addressing to improve access to and quality of health care. Providing evidence that may help improve health care services for the elderly in Zimbabwe and other sub-Saharan African countries is of paramount importance as this impacts their well-being.

The health belief model appears to hold promise to advance understanding of perceived health and well-being in caregivers (Taylor, 2013). The health belief model explains and predicts health-related behaviors, particularly regarding the uptake of health services. Grandparent caregivers may perceive susceptibility to poor health and that certain diseases are severe with grave consequences. They may believe that accessing health services can overcome barriers and enable coping and managing of the diseases. If the caregivers do not see a health care behavior as risky or threatening, there is no stimulus to act. If perceived as risky, caregivers may have the expectation that seeking health services will be beneficial.

Goals of the Study

This article focuses on the qualitative part of the study. The in-depth interviews corroborated and expanded on collected survey data, providing meaning to different experiences. The purposes for mixing were expansion and complementarity. The interviews helped explain the survey findings, therefore enhancing the study's validity.

The objectives of this part of the study were:
1. To explore the perceptions and lived experiences of self-rated health, access to, and state of health services for grandparent caregivers in Zimbabwe.
2. To identify perceptions of instances of stigma and discrimination that affect health-seeking behavior by grandparent caregivers.

Method

The qualitative approach used enabled caregivers' perceptions to be uncovered through direct questioning to complement the quantitative data. In–depth interviews using semi-structured interview guides were carried out to elicit lived experiences from the key informants. Narratives or stories of people's lived experiences, local histories, and shared knowledge to understand systematic behaviors were recorded. The qualitative data that were generated was analysed thematically. The descriptive data gathered from the semi-structured, open-ended interviews contributed to understanding grandparents' perceptions of self-rated health and health services.

Setting and Participants

Zimbabwe is a landlocked country, bordered by South Africa, Zambia, Botswana, and Mozambique and made up of 10 provinces. Two of the 10 provinces of Zimbabwe (Harare and Mashonaland East) were selected as the sampling frame. Harare province is made up of seven districts, and Mashonaland East is made up of eight districts, mostly rural and farming area. The socioeconomic indicators and the prevalence of caregiving by grandparents in the chosen provinces are similar to the other eight. Most participants were primary caregivers.

Grandparents met the inclusion criteria if they were able to speak and understand Shona and/or English and were fostering grandchildren under 18 years of age. The 31 participants for this part of the study were selected from the total quant-qual sample (400) using purposive sampling so as to include different demographics (heterogeneous sampling). Nineteen participants resided in an urban setting (10 low-density and 9 high-density suburbs) and the other 12 resided in a rural setting. It had been anticipated that a maximum of 50 people would take part in the qualitative study but saturation (i.e., new ideas or opinions ceased to come up) was reached with 31.

Data Collection Procedures

Approval to conduct research was given by the University of Sydney Ethics Committee and The Medical Research Council of Zimbabwe. Qualitative in-depth interviews with grandparent caregivers were used to collect data and the interview guide was piloted on two participants and adjusted for clarity. The in-depth interview question guidelines covered self-rated health of caregivers, perceptions of access to health services, perceptions towards state of health services and coping strategies, and prejudice, stigma, and discrimination. Questions probed lived experiences of caregivers in relation to their health, access and state of health services and discrimination. For instance, questions like "How has been your health?" and "How do you cope with being a caregiver for orphans?" and others were asked. Generally, questions asked were about health and services, fulfilment, or negative experiences the grandparents have encountered from carer responsibilities. The open-ended questions improved the research process and enabled greater insight. All data were collected in the local language for the sampled districts.

Data on the caregivers' demographics and socioeconomic characteristics were also collected. Most of the respondents were interviewed at times convenient to them in their homes or outside the house. The latter was because there was no privacy in some of the homes because of overcrowding in certain communities (e.g., high-density suburb and farming areas). The investigator explained the purpose of the study and scheduled interviews with the participants. The caregivers signed consent forms or used a thump print if illiterate. They also had to consent to the use of tape recorders to record interviews. Participants were assured of confidentiality and anonymity. The author conducted the interviews, and each lasted about 60 minutes.

Data Analysis

After all data was collected, it was transcribed verbatim and the transcriptions were checked for accuracy against the audio tapes. The data was thematically analysed, and the software Nvivo 10 (Bazeley & Jackson, 2013) was used to help categorize emergent themes. The links between the themes to show prevalent thematic codes and mind maps were also drawn in Nvivo 10. Similarities, differences, and variations with other themes were determined using comparisons. The in-depth interviews provided meaning to different lived experiences. They added an explanatory detail on how the caregivers accessed health services despite limited resources and the state of health services in Zimbabwe. The recorded observations, feelings, and impressions that were written in a notebook during data collection so as to remember the reflections when transcribing was added in memos and annotations in Nvivo 10 during organization.

Results

Data analysis revealed four overarching themes that described the lived experiences of grandparent caregivers for orphans. The themes that emerged included: 1. The self-rated health status of caregivers and that of household members; 2. perceived access to health services and strategies for coping; 3. perceptions of health services in grandparent caregivers' communities; and 4. prejudice, stigma, and discrimination experienced by grandparent caregivers. Verbatim quotes are used to explain the themes where possible.

Socio-demographic Characteristics of the Population

A total of 31 grandparents (74% female) participated in this section of the study. Their ages ranged from 45-92 years (M= 65.7, SD= 10.7), with 26% in the 56-60 year age group. Of the caregivers, 13% were university graduates, 45% were primary school graduates, and 29% were high school graduates. Most of the caregivers were widowed (63%). The grandparents received income from work, self-employment, rentals, and support from their adult children. The average monthly income was 300USD. All the caregivers with the exception of one were religious and were actively involved in religious activities. Grandparents took up caregiving because the children's parents had died from AIDS (57%), were living in multigenerational households (33%), or the children's parents could not stay with their children (10%). Most of the caregivers got support (financial, social, physical, and emotional) from their surviving children (67%). Each carer fostered an average of three grandchildren (54% were orphans and the rest non-orphans). Thirty-five percent of caregivers were fostering orphans only, 19% non-orphans, and 45% were taking care of both orphans and non-orphans. Of the 96 grandchildren fostered, 20% were reported to have tested HIV-positive. Most of the caregivers were fostering maternal grandchildren (55%), paternal (13%), and both maternal and paternal (32%). Nine percent of the children were not in school because

their caregivers could not afford to pay school fees.The themes that were identified are elaborated in the next section. It should be noted that the themes overlap.

The Perceived Self-Rated Health of Caregivers and Household Members
The results under this theme showed the oneness, unity, and solidarity among African communities. In African societies, oneness and sharing play a vital role. Caregivers reflected the aspect of collectivism in their health-related narratives. When asked how their health had been, grandparent caregivers included the health of all members living in their households.

Twenty-six participants (87%) reported their self-rated health as bad. The prevalence of physical limitations increased with age. High blood pressure (HBP) (8), arthritis (7), back pain (9), generalized pain (6), and HIV opportunistic infections (21) were recurrent words in participants' responses. The other ailments that were mentioned were heart problems, continuous cough, visual and hearing problems, headaches, and asthma. For instance, a carer reported the self-rated health status of people in her household:

> *…I am depressed…My husband died in January this year from prostate cancer…We were eight in my family and six of my siblings died from HIV. Out of my seven grandchildren, four have tested positive. My other grandson who tested positive died last year from meningitis at 2 years…My son is mentally ill and I have to take him to Annex [mental health facility] for medication. He walks naked when sick…My four surviving daughters have all tested positive…My sisters left 10 children and my brother left four. AIDS is a disease that is prevalent in this house.…*
>
> (Participant 28; 57 years, female, rural)

This participant reported having several members of the household unwell particularly from HIV opportunistic infections. Four of the caregivers in the study divulged they were living with HIV and AIDs, and most caregivers had a spouse, children, relatives, and/or grandchildren who were living with HIV or had died from AIDs. Other caregivers cited their bad health and that of their husband, their adult children, and their grandchildren:

> *…I am asthmatic and have high blood pressure (HBP) and I take hydrochlorothiazide (HCT). My husband was positive, but he did not tell me…I found his ARVs after he had died under the mattress…he was very promiscuous…One of my grandchildren is also sick and the parents are HIV-positive.*
>
> (Participant 25; 65 years, female, rural)

> *My health is not very good. I suffer from arthritis, hearing problems and visual. My wife has HBP. We cannot afford to go to the clinic for it is far off. At times we get headaches and do not sleep well because of problems.…*
>
> (Participant 7; 79 years, male, low urban)

*I have diabetes, gout, and ulcers...I am just a domestic
worker and I earn very little. I am stressed because I live
in a high socioeconomic status (SES) suburb and the fees
are high...I cannot afford paying fees for two children
(daughter and grandson) from my salary.*

(Participant 9; 54 years, female, low urban)

*My health is not good. I am HIV-positive and am on
ARVs and cotrimoxale...plus arthritis...My husband is
also positive. We do not have sex because we were
separated long back. I also consult apostles/religious
leaders when I have a problem because I don't pay.
Sometimes I take herbs to control my illness.*

(Participant 14; 69 years, female, low urban)

Four caregivers (13%) reported health challenges resulting from caregiving roles. An excerpt to illustrate this point:

*I am always sick; my health is poor, particularly at
night. Ohhh oh....I feel generalized pain, a
headache...I feel I will die especially at night. I also
feel shoulder pain. I work a lot during the day because
I look after six orphans and cannot rest at night
because of the pain. Caregiving is hard work and it
makes me sick. There is no one to help me with chores.*

(Participant 24; 68 years, female, rural)

Four caregivers (13%) reported health challenges resulting from the aging process. For example, an excerpt from a caregiver:

*I have generalized pain...But manageable...I think
pain is from old age, not `caregiving. My wife was
asthmatic, and she died in 2005.*

(Participant 15; 60 years, male, low urban)

Good physical health and positive perceptions are important for caregiver roles in general and for aging persons. For example, positive perceptions allow caregivers to recover more quickly, improve their ability to self- regulate, and buffer against energy depletion from care provisioning (M Mhaka-Mutepfa, 2018). This theme on the perceived self-rated health of caregivers leads to their perceived ability to access health services and strategies for coping.

Ability to Access Health Services and Strategies for Coping
Three caregivers reported they did not seek medical care because they could not afford the costs. Clinics in rural areas were located at a long distance for some caregivers and the caregivers had to commute. For instance, a grandparent said:

*I do not go to the clinic, I cannot afford it...I get onto
a bus...pay for the card and get a prescription. My
grandchildren have no food and are not going to*

> *school. I only went back to the clinic once after I was*
> *bitten by a scorpion, but I was made to pay...I didn't*
> *have the money and they took my ID until I had paid*
> *despite being over 65.*
>
> (Participant 24; 68 years, female, rural)

There is no monitoring of services and some corrupt health personnel may ask patients to pay for services even if they are over 65 years old.

Another grandparent caregiver reported two issues. One issue was on length of treatment and the other on failing to seek medical care. She attributed getting well to luck.

> *When my four children were sick, they died. We were told*
> *to take them home. I guess the nurses knew they were*
> *dying and wanted to preserve beds for those who could*
> *recover. They were not given proper medication except*
> *Panadol and were kept in hospital for a short time. I*
> *hardly go to the clinic although I have back pain because*
> *of lack of money, I just ignore my pain...At times I get*
> *herbs from the traditional healer a few houses away. Two*
> *of my grandchildren who tested positive are always sick,*
> *but I cannot afford to go get free ARVs from the clinic.*
> *Moreover, the nurses are moody. I do not know how to*
> *help my grandchildren except give them herbs. Poverty is*
> *the same as dying.*
>
> (Participant 3; 62 years, female, rural)

> *I just went to hospital because friends said my ailment*
> *needed a doctor [coronary heart disease; CHD],*
> *otherwise I would have seen a sangoma [traditional*
> *healer]. They are cheaper. Going to hospital is the same*
> *as staying at home. They do not provide quality care for*
> *the sick...They make you wait even if you cannot breathe.*
> *…Without money they do not treat you…I will not go*
> *back.*
>
> (Participant 31; 79 years, female, rural)

> *My eldest grandson is worse than me. He picks rubbish*
> *and is violent when not on medication. His medicine is*
> *finished… It costs 17 USD. My other grandchild has*
> *symptoms of HIV but has not been tested. He is always*
> *sick.*
>
> (Participant 21; 75 years, female, high urban)

Chronic illnesses may cause depression and anxiety, which influence medication adherence (Taylor, 2013) and seeking services, particularly to caregivers on anti-retroviral drugs and those with diabetes or CHD. Management of chronic illnesses is important for self-esteem and self-concept (Taylor, 2013), especially for elderly caregivers and their grandchildren. This influences their health-seeking behaviour. A caregiver had this to say:

> *I have CHD and I am depressed. I was referred to a*
> *specialist but I have no money. One of the nurses told*
> *me to try a traditional healer but I am prayerful.*
> *Poverty is the problem and I worry a lot. I lost my*
> *children to HIV and I have to take care of my five*
> *grandchildren...We went to see religious advisers but*
> *there is no change. However, I feel better because I*
> *have taken action.*
>
> (Participant 30; female, 62 years, rural)

Perceptions Toward State of Health Services in Grandparent Caregivers'
Communities

Twenty-two grandparent caregivers (73%) expressed lack of satisfaction with
health services in the country. Eight caregivers (three low urban, four high urban, one
rural) were somewhat satisfied. Those who were satisfied mentioned access to medical
insurance, free medication at times, free consultations, and good service at some clinics.
For instance, a grandmother who resided in a low-density urban area (high SES)
illustrates her satisfaction:

> *I am satisfied because each time I go to the clinic they*
> *ask me how I am feeling, and they give me free*
> *medication.*
>
> (Participant 14; 68 years)

Dissatisfaction with health services in general was a recurrent theme by
caregivers (seven urban low, five urban high, eleven rural). An excerpt from one of the
grandparent caregivers who was not satisfied with health services:

> *The health services leave a lot to be desired. My*
> *child had an accident and I feel more could have*
> *been done...My daughter gave birth and she died*
> *from HBP. They attend to patients late as if they do*
> *not get paid, and it is worse if you are known to be*
> *HIV-positive. They shun you.*
>
> (Participant 16; 58 years, female, low urban)

Twenty six caregivers (87%) complained of long queues, inadequate personnel
and medication shortages, expensive consultations, and poor service in general,
particularly at large hospitals. Caregivers from the different residential areas expressed
similar sentiments. For example:

> *...Health services in our country need divine*
> *intervention, long winding queues at hospitals, no*
> *specialists, drugs and lack of courtesy. You arrive at*
> *8 a.m and you may be attended to the following*
> *morning. I would rather get treatment from a*
> *traditional healer.*
>
> (Participant 12; 64 years, female, low urban)

One grandmother who resided in a rural area spoke of better treatment for HIV and AIDS and mental illnesses but not cancer as follows:

> *...if people had not discovered ARVs, I would have lost all my children. I am satisfied with the way they treat AIDS. If they were not good at it...Cancer, aaa [shakes head], they still find it difficult 'cause they could not treat my husband...health services at Annex are better, my son (mentally ill) has improved...My daughters are also alive 'cause of ARVs ...same applies to my grandchildren.*
>
> (Participant 28, 57 years, female, rural)

Five caregivers (17%) reported that they got ARVs, hydrochlorothiazide (HCT), salbutamol, and other common drugs for free if available at clinics. Other ailments and medications had to be paid for especially if patients were referred to specialists. A grandparent said:

> *I have heart problems. I am on medication, but it is not working. I was referred to a private specialist doctor but I have no money. I cannot work because I feel tired. I have had this problem for almost two years and will eventually die because I cannot pay a specialist. My friends suggested traditional healers because they do not want money upfront, but I am a Christian.*
>
> (Participant 29, 79 years, female, rural)

A grandparent made an observation that knowledge of ailment determined whether caregivers are satisfied with the state of health services. She stated:

> *I am not satisfied because they don't give us information. People lack knowledge on ailments and treatment...Relatives should accompany their sick to assist in issues like taking medication correctly. I accompanied my sick daughter...I was given information on how to provide quality care to an HIV-positive patient...Now I care for my daughter and her children without any qualms.*
>
> (Participant 20; 58 years, female, urban high)

Caregivers residing in urban areas reported the need for clean water and electricity as these were perennial problems and affected the state of health services. They also needed their own accommodation, and those with houses in high density urban suburbs (low SES) needed better accommodation as they were crowded. Other caregivers shared a room with their children and grandchildren in one section of the urban high density area. An excerpt to illustrate these points:

We need water, electricity, it is hardly available.
And...Accommodation. Sewage is flowing everywhere,
the toilets are blocked and 11 of us live in one-
room...there is rubbish everywhere...The nurses tell
you to go and fix sugar and salt solution for your
diarrhoea at home. Most of the times we are treated
badly...We have to carry our own water. The hospital
toilets have poo... I have HBP and I get HCT for free
at times, however, I am so depressed because of my
living conditions and the sick people around me. I do
not always take my medication because either way I
will still die. If not from the HBP, maybe I will die
from the dirty water we drink, sewage, or depression. I
cannot even tell them I am depressed. People with
poor mental health are ridiculed.

                                    (Participant 1; 65 years, male, urban high)

Prejudice, Stigma and Discrimination

Four caregivers (13%) reported stigma and discrimination. Two caregivers (7%) said extended family members accused them of killing their children. Excerpts to illustrate this point:

I was accused of killing them by my husband's relatives.
When he died, they took everything...and they do not
talk to us. They called me a witch.

                                    (Participant 25; 61 years, female, rural)

This community does not really support each other. They
say I murdered my husband. Family members are not
supportive either except friends from church...My
relatives are not supportive; they say I bring misfortune
on myself because I killed my husband.

                                    (Participant 5; 59 years, female, rural)

I had a difficult marriage and the community was not
supportive. They talked about my husband's health and
that he had died from AIDS. Some stopped talking
about it when I joined a support group and announced
my positive status. However, others shun the members
of the support group.

                                    (Participant 10; 57 years, female, rural)

Another carer experienced stigma because she was staying with an orphan who was living with HIV and AIDS:

My employers used to help me before...I was told my
grandchildren were not my children, so I should not live
with them. They do not want my granddaughter to play
with their children because she is positive. They also do
not talk to her; I have to keep her in the servants'
quarters.

(Participant 9; 54 years, female, low urban)

The grandparent caregivers above experience stigma and discrimination. In addition, negative evaluation of the caregivers and their grandchildren based on group membership was present. When the need to interact and belong is denied through prejudice and stigmatization, it can have disastrous consequences to the health of the stigmatized person. Isolation of others may impair quality of life and well-being (Steptoe, Shankar, Demakakos, & Wardle, 2013) and may lead to depression.

Discussion

The excerpts in this paper express difficulties in accessing health services and the poor state of health services in Zimbabwe. Caregivers' lived experiences and insights offer a unique perspective of the health system and how the elderly are handled. Many undocumented aspects, known only to the caregivers who visited health services, were revealed, highlighting issues which are relevant to improving the care quality in Zimbabwean health systems. Health outcomes are dependent on access and quality care at health facilities, and effective management across the health system. Caregivers avoided facilities perceived as unhelpful, thus failing to access health services. Resources determined how often caregivers sought medical services, hence the need for meaningful intervention.

Other caregivers resorted to traditional healers and religious leaders for health services because they could not afford conventional medicine or had no access to it. For some caregivers, traditional healers and religious advisors were a strategy for coping with chronic illnesses and depressive symptoms since most grandparent caregivers could not access health services in the current study.

Self-Rated Health, Access to Health Services and Strategies for Coping

Grandparent caregivers with access to health services and other resources had better self-rated health than their counterparts regardless of whether they were fostering orphans or non-orphans. The finding contrasted the quantitative study in Zimbabwe that found that grandmothers fostering orphans lacked psychosocial support and had poorer mental health than those fostering non-orphans (Howard et al., 2006). However, Howard et al (2006) did not look at the utility of resources. Resources (e.g., support, income, social networks) were found to positively impact the health and well-being of caregivers (Mhaka-Mutepfa et al., 2015; Cheng et al. 2013; Mugisha et al., 2013; Sayegh & Knight, 2011). Likewise, perceptions of access to health services and state of health services were found to impact caregivers' health and wellbeing. However, access was impeded by lack of social protection and the state of health services. This finding was similar to reports from previous researchers in Uganda and Zimbabwe that not many caregivers benefit from social protection and health services in low income countries (Kamya & Poindexter, 2009; Pufall et al, 2014). This is because the countries are poor and cannot provide social protection and health services to all the needy people.

The current study found that grandparents experienced multiple chronic and complex self-rated health conditions (e.g., arthritis, diabetes, hypertension, back pain, and heart problems) which influenced their health and well-being. Poor health has a negative effect on caregivers' well-being if they do not seek health services. For example, back pain is one of the most common cause of disability in most countries and large numbers of elderly people deal with it on a daily or intermittent basis (Taylor, 2013). Chronic illnesses have a negative effect on caregivers' well-being, suggesting the importance of providing caregivers access to health services. Their grandchildren also fail to access

health services because their guardians are poor and some of them fear ridicule.

Nevertheless, caregivers in Zimbabwe were expected to get free treatment in public health centres after they attain age 65. However, this benefit only applies to public health services as mentioned by participants 24 and 30. Similarly, long queues, lack of immediate attention for seriously ill patients (shortage of human resources and drugs), delays after arriving at the healthcare facility, and being made to pay for health services in most healthcare centers, including some public health centers, have been reported before (Jones et al., 2016, Dhemba & Dhemba, 2015; Newsday, 2015). Grandparent caregivers thus perceive going to public health facilities as a waste of time, thereby impacting their health and well-being. In addition, younger grandparent caregivers (below 65 years) were not benefiting as they always had to pay for health services. Overall, costs of drugs and transport remained prohibitive, particularly in rural areas. Grandparents had to travel long distances to the city to buy drugs from pharmacies, despite lack of resources. These findings are consistent with previous studies (US Census Bureau 2012; Dhemba & Dhemba, 2015). Urban residents (60%) in Zimbabwe had better self-rated health than rural residents (8%) just like participants in previous studies in Ghana and South Africa (U.S Census Bureau, 2012). Health services (e.g., public hospitals and clinics) were more available in high density suburbs as these suburbs are densely populated. Despite the differences in numbers of health services, all groups had similar perceptions to self-rated health problems (arthritis, diabetes, HBP, back pain, etc).

A few caregivers (13%) mentioned seeking health services of traditional healers and/or religious advisors. Most of the grandparent caregivers (93%) were Christians and some of them would find it difficult to reveal seeking services of traditional healers as an alternative. This is because seeking health services of a traditional healer is often perceived as lack of faith in God. Christians in Zimbabwe believe God is insulted when we seek services from other beings, hence they may not mention using traditional healers as a strategy. However, the services by healers were perceived to play an important role in the delivery of mental health care in parts of sub-Saharan Africa including Zimbabwe (Madamombe, 2006). Western medicine is generally accepted throughout sub-Saharan Africa, although it has not replaced, but rather augmented indigenous health approaches.

Prohibitive medical costs also make it difficult to get medical attention so the poor resort to traditional healers who do not always demand cash up front and have no herb shortages. The Zimbabwe government, in 2002, regularized traditional medicine and this affects adherence (participant 14). This participant 14 was mixing pharmaceuticals and herbal medicine. Similar to findings by Madamombe (2006), some patients may disregard their doctor's advice or take herbal medicines that could have dangerous interactions with pharmaceuticals. Many patients fall victim to remedies that have not been tested and are offered outside the formal healthcare system. Despite the anomalies above, grandparent caregivers also had negative perceptions on the state of health services.

Perceptions of State of Health Services in Grandparent Caregivers' Communities

Most of the caregivers (73%) expressed negative sentiments on the state of health services. Perceptions of the state of health services may impact caregivers' willingness to seek health services when needed. A few who resided in the upmarket suburb (low-density suburb) and had medical insurance had positive feelings towards the state of health services. They sought services of private doctors and hardly visited public clinics. Generally, health personnel in private health care facilities are not overwhelmed, are paid handsomely, have drugs, and are bound to provide quality care to patients.

However, other caregivers who lived in the same area had different lived

experiences from public hospitals consulted (participants 1 and 16). They reiterated the negative attitudes of health personnel and these seem to be reciprocated in the elderly caregivers. The caregivers' high rates of disease morbidity coincide with a lack of requisite primary health care. For instance, about 96% of the elderly with hypertension in Ghana have inadequate treatment (Lloyd- Sherlock , Beard , Minicuci , Ebrahim , & Chatterji 2014), just like caregivers in the current study. Most caregivers in both studies had no confidence in the state of health services. This finding is in stark contrast with Taylor's (2013) report in the USA that 54% of caregivers expressed high confidence in physicians. However, patients seeking psychological intervention (e.g., for depression or anxiety) in both high and low-income countries were said to evoke negative reactions from physicians (Taylor 2013), which was the case in this study. Attention by health personnel can be cursory regardless of type of economy as expressed by participant 1 and 16 above.

However, that may not be the only problem. Consistent with current findings, as people age, the number of medical problems increases, and people's ability to report their symptoms correctly and follow treatment guidelines decreases (Taylor, 2013). Taylor posited that 40% of people over 50 years have difficulties understanding instruction for their medication. They also may not comprehend why they have to adhere as stated above (participant 1), therefore they may not seek health services. Failure to adhere does not help chronic conditions which lead to reduced health related well-being (Taylor, 2013). Seeking health services and well-being are also affected by prejudice, stigma, and discrimination.

The Impact of Prejudice, Stigma, and Discrimination
Stigmatizing grandparent caregivers is likely to affect whether they seek medical services or not, thereby impacting their self-rated health and well-being. Because of prejudice, stigma, and discrimination attached to AIDS, the role of full-time caregiving has tended to diminish the elderly's status, and their roles are often undervalued and viewed negatively (Kidman & Thurman, 2014; Yancura & Greenwood, 2013). However, current findings are inconsistent with previous findings in other sub-Saharan African countries that revealed that stigma and discrimination was rampant and was perpetrated by professionals, particularly health personnel. Stigma was present in Zimbabwe but not as rampant as it was a decade ago (Mhaka-Mutepfa et al., 2015). Sixteen percent of caregivers were affected by stigma in the current study, possibly because more people now understand the negative impact of stigma and almost everyone in the communities have someone close to them that has tested HIV-positive (requiring health services) or succumbed to the disease.

Nonetheless, prejudice, stigma, and discrimination were found to affect social relationships among caregivers, their extended families and communities, and whether caregivers would access health services. Social relationships are central to human well-being and are critically involved in the maintenance of health (Taylor, 2013). Isolation and emotional distress, proxies for stigma, become prominent problems at older ages due to stigma attached to HIV/AIDS (participant 9, 10, and 16), thereby limiting social networks (Marlatt-Carlini, 2005; Willie-Tyndale et al., 2016). In addition, grandparent caregivers taking care of their grandchildren may also get isolated because they are doing chores that are different from activities done by their cohort. However, anti-stigma advocates in Zimbabwe run campaigns to raise awareness of the struggles of the stigmatized in hopes of breaking down stereotypes and building empathy and support. Methods of advocacy focus on getting to know the stigmatized, share life stories, answer questions, and encourage them to seek health services. The repercussions for stigma and

discrimination may be irreversible (e.g., imminent death or suicide), hence there should be zero tolerance to stigma.

Policy Implications and Limitations

The implications originating from this study would benefit most sub-Saharan African countries as they all have grandparents as caregivers to children and experience similar chronic conditions. They may have similar perceptions and lived experiences to access and state of health services. A system-wide approach is necessary to highlight where improvements could be made, which could benefit ill caregivers and ill children particularly in more resource-limited settings (Jones et al., 2016).

The findings suggest several interventions, which might improve and optimize the health system. Health personnel have to be professional to enable caregivers to seek services. Resources and health insurance should also be made available to the caregivers to enable accessing of health services. There should be an emergency route for serious health problems (e.g., CHD) and health promotion for adherence.

Previous studies reported that the number of non-orphaned fostered children were almost the same as fostered orphans in southern Africa (Grant & Yeatman, 2012; Hampshire et al., 2015) and so does the current study. These findings imply that all grandparent caregivers should have health insurance and should all benefit from social protection. National interventions are critical to boosting the pension coverage among the Zimbabwean populace to ensure financial independence in old age, and this action could change their perceptions of health services. With finances, grandparent caregivers can access health services of their choice (McKoy et al., 2017) and reduce the long queues in public health facilities.

The presence of non-communicable diseases (NCDs) among grandparents indicates the need for regular access to quality health care and/or services. The state of health services was lamented by most caregivers particularly in rural areas. Authorities must identify preventable failures in the care provided, through provision of health insurance, training health personnel to be empathetic, increase human resources, and avail drugs. A government drug subsidy programme can be introduced for the elderly. It is also difficult to provide quality health services without working on the determinants of health, especially eradicating poverty.

Future studies on grandparent caregivers should look into problems of accessing health services using large quantitative studies to generalize findings. Future research should also explore the perceptions of clinicians or health personnel as well as grandparent caregivers. Participants may have provided inaccurate accounts which may not be factual or representative of general experience (Jones et al., 2016). Responses of grandparent caregivers with chronic health conditions may have been influenced by their frail health.

Policies on health need monitoring and evaluating to ensure effective implementation. Under-developed and poorly implemented social welfare policies should be revisited. The Older Persons Act of 2012 could be updated and implemented as grandparents were not benefiting from public health services. African countries have a propensity of failing to implement policies, and this failure draws back development (Kaplan & Perez-Porter, 2014).

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Book Review

Grandparents Raising Grandchildren: Expanding Your View
A Guidebook for the Kinship Caregiver (2018)
by
Linda Dannison, PhD
Andrea Smith, PhD

This gem of a book is intended for grandparents who have the full-time responsibility of raising their grandchildren as a means to support their resiliency and capacity for growth in this often-challenging role. Although much has been written about the stress of kin caregiving, there is a dearth of available literature that is practical, hands-on and designed as well as this book. It can be used by kin caregivers on their own, with a partner or friend or in support groups to enhance their sense of well-being, sustain their ability to function effectively in their caregiving role and remain committed to doing so.

Each of the 7 themed chapters leads with a timely quote, provides psycho-education and information, then offers 3 weekly relevant activities and tools to help expand their views, and closes with possible resources. Of particular note, is that it includes a specific option for "veterans," the seasoned caregiver who may have a unique and longer lasting perspective. Each chapter offers many valued ways to enrich the conversation and develop new ways to approach challenges. The importance and theme of gratitude as a sustaining force is woven effectively throughout it.

The chapter topics are:
- Your Grandfamily
- Recognizing Your Needs
- Self-Care
- Resiliency Snapping
- Building Strong Relationships
- Building Childhoods
- Rediscovering Your Passion and Joy

The accessible activities in each are tailor made to address the issues that are raised and are innovative, creative, purposeful and focused. Caregivers can benefit tremendously from utilizing these tools and techniques which have the potential to balance and off-set the many stressors they face.

Authors Dannison and Smith are widely respected and very knowledgeable about kincare families, having devoted much of their professional lives to building awareness about the role of these families from a strengths perspective. The authors bring a wealth of insight and clinical skill to the book which makes it approachable, validating and highly beneficial to kin caregivers.

Deborah Langosch, PhD, LCSW
Director, The NYC Jewish Board Kinship Care Program

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, and advancing the work of practitioners and scholars in the development, implementation and evaluation of new knowledge in the field.

Core Beliefs
Grandparents contribute to the preservation of whole 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 assume parental responsibilities.

Communities are better served by grandparents taking on the custodial care of their grandchildren, when needed.