



Grandparents Raising Grandchildren: A Review with Implications for Grandparents Raising Grandchildren with Disabilities

Torunlarını Büyüten Büyükanne ve Büyükbabalar: Engelli Torunlarını Büyüten Büyükanne ve Büyükbabalara Çıkarımlar İçeren bir İnceleme Yazısı

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Abstract

Research involving families of children with disabilities has focused mainly on parents, particularly mothers, but the extended family, including grandparents, should also be examined. This review synthesized the literature from 1990 to 2013 regarding the subject of grandparents raising grandchildren, particularly grandchildren with disabilities. We also examine sources of support and family quality of life of grandparents raising grandchildren. Implications for those working with families in schools as well as suggestions for future research are presented.

Öz

Engelli çocukların ailelerini konu alan çalışmalar çoğunlukla ebeveynler, özellikle de anneler üzerine odaklanmıştır. Ancak bu alanda büyükanne ve büyükbabanın da yer aldığı geniş aileler üzerine de çalışmaların yapılması gereklidir. Bu yazıda 1990-2013 yılları arasında torunlarını özellikle de engelli torunlarını büyüten büyükanne ve büyükbabaları konu alan çalışmalar biraraya getirilmiştir. Ayrıca yazıda torunları büyütmede destek kaynakları ve büyükanne ve büyükbabanın yaşam kaliteleri de ele alınmıştır. Bu konuda okul ortamında ailelerle işbirliği yapanlar ve gelecekte bu konuyu çalışacak araştırmacılar için önerilerde bulunulmuştur.

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1. Introduction

The family is regarded as the primary and most powerful system to which a person belongs (Seligman & Darling, 2007). No matter the makeup, family has been defined as “two or more people who regard themselves as a family and who carry out functions that families typically perform” (Turnbull, Turnbull, Erwin, & Soodak, 2006, p.7). The family constellation has gradually changed over the years; no longer is the “traditional” family of two parents and several children considered the norm in many countries. Family

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composition now takes many forms such as single parents, grandparent(s) with adult child and grandchild, and grandparents alone raising grandchildren. Indeed, grandparent-headed households have joined the list of contemporary family units. Though there are many grandparents who are involved in various part time ways in the lives of their grandchildren, this review focuses on custodial grandparents who serve as the main caregivers raising their grandchildren.

Custodial grandparenting has assumed a variety of forms such as co-parenting with an adult child, acting as sole custodial parent, or dual parenting with a spouse (Hayslip & Kaminski, 2008). A disproportionate number of grandparent-headed families are raising grandchildren with learning, behavioral, and/or developmental disabilities, often due to the prenatal and/or postnatal experiences of the grandchildren, which can include drug exposure, abuse/neglect, and inadequate care (Brown & Boyce-Mathis, 2000; Silverstein & Vehvilainen, 2000). These second-time parents play a central role in determining the developmental outcomes of the children in their care, whether the children have disabilities or not (Hayslip & Kaminski, 2008).

2. Method

For this review, the authors examined and synthesized the literature from 1990 to 2013 regarding the subject of grandparents raising grandchildren, particularly grandchildren with disabilities, in both U.S. and international journals. Galileo, ProQuest, and EPSCO host search engines were searched using the following categories: ERIC, PsycARTICLES, PsychEXTRA, Psychology & Behavioral Sciences Collection and PsycINFO, with these search terms: *grandparents/grandmothers raising grandchildren, grandparent caregivers, grandchildren with disabilities, kinship care, and custodial grandparenting*. References in the articles found from this search were also used to find additional studies and relevant books. The current review will define and outline characteristics of grandparents providing custodial care, review the research literature on both positive and negative consequences of custodial grandparenting in general, review the literature on consequences of custodial grandparenting for those grandparents raising grandchildren with disabilities, and finally review the literature on two specific areas, sources of support and quality of life, both overarching areas of focus within the family literature on grandparents.

3. Discussion

3.1. Custodial Care

Grandparents assume full-time custodial care of their grandchildren for a multitude of reasons, though assuming care usually occurs in the context of a family trauma and can be highly stressful (Jendrek, 1994; Shore & Hayslip, 1994). Researchers have identified maternal substance abuse and the often resulting child maltreatment as the primary reason grandparents assume responsibility of parenting their grandchildren (Dowdell, 1995; Jendrek, 1994; Kelley, 1993; Minkler & Roe, 1993). Other contributing factors include: (a) parental death (Fuller-Thomson & Minkler, 2000a); (b) incarceration of the biological mother (Fuller-Thomson & Minkler, 2000a); (c) mental illness of a parent (Dowdell, 1995); (d) abandonment (Pruchno, 1999); and (e) early teen pregnancy (Hayslip & Kaminski, 2005a).

Such assumption of care can be unanticipated and involuntary, often resulting from unforeseen circumstances. The custodial relationship may be permanent (e.g., through the death of a parent) or temporary, depending upon the circumstances of assuming care (Burnette, 1999; Minkler & Roe, 1993). Despite the possibility of indefinite custody, many grandparents assume responsibility for the grandchildren because they believe they are the only person who can keep the child out of the public foster care system (Cox, 2000; Goodman & Silverstein, 2002) or they believe they can provide better care than the parent (Hayslip & Kaminski, 2005a). In addition, grandparents offer to care for their grandchildren in order to help their own adult children in times of crisis (Hayslip, Shore, Henderson, & Lambert, 1998). The common thread among grandparent caregivers appears to be the commitment to the well-being of their grandchildren (Jendrek, 1994; Minkler & Roe, 1993).

3.2. Characteristics of Custodial Grandparents

Custodial grandparents or grandparent caregivers are defined as adults who have primary responsibility for their grandchildren younger than 18 years of age on a full-time basis (Hayslip & Kaminski, 2005b; U. S. Bureau of the Census, 2003). In the U. S., according to the Pew Research Center's (2010) analysis of the Census Bureau data, approximately 2.9 million grandparents have primary responsibility for their grandchildren; 39% of them have been caring for their grandchildren for five or more years. Forty-nine percent of children being raised by grandparents also live with a single parent (Pew Research Center, 2010). However, for forty-three percent of children being raised by grandparents, there is no parent in the household (Pew Research Center, 2010). These "skipped generation" family units, where grandchildren and grandparents live together with neither parent present, have become the most rapidly increasing living arrangement among contemporary families in the U. S. and elsewhere (Fuller-Thomson & Minkler, 2000a).

Custodial grandparenting appears to have no ethnic or socioeconomic boundaries and all groups have been impacted by the assumption of the parenting role. For example, in the U. S., when examining grandparent-headed households by ethnicity/race, 54% are Caucasian, 31% are African American, and 11% are Hispanic/Latino (U. S. Bureau of the Census, 2005-2007), though proportionally, grandparent caregivers are over-represented within African American (4.3%) and Latino (2.9%) households when compared to Caucasian (1%) households (Fuller-Thomson & Minkler, 2000a; U. S. Bureau of the Census, 2001b).

3.3 Income

Many grandparent-headed households live at or below the poverty level. In the U. S., for example, the percentage of grandparent caregivers living below the poverty level (19%) is greater than that for other types of families with children (14%; U. S. Bureau of the Census, 2001a). Fuller-Thomson, Minkler, and Driver (1997) found that grandparent caregivers are 60% more likely to live in poverty than grandparents not raising grandchildren, with grandmother-headed households being the most impoverished. In fact, two-thirds of those children living in grandmother-only headed households are living in poverty (Bryson & Casper, 1999).

3.4. Work Issues

Employment issues often arise when grandparents begin raising their grandchildren. Grandparents who are employed may have to give up working outside the home in order to raise their grandchildren, thus losing much needed income and putting their own future economic well-being at risk (Hayslip & Goldberg-Glen, 2000; Musil, Schrader, & Mutikani, 2000). For retired grandparents, whose income may already be limited, the lack of adequate assistance from government agencies and the increased expenditures force many to either draw from their retirement or savings accounts, cash in life insurance policies, or return to the work force (Beverly, 1995; Minkler & Roe, 1993). Providing for the family becomes even more difficult with multiple caregiving demands (Beverly, 1998) or when there are grandchildren with disabilities within the family. In addition, lack of financial stability may compound other difficulties faced by these families (Hayslip & Goldberg-Glen, 2000).

3.5. Gender and Age of Grandparents

The majority (63%) of all grandparent families in the U. S. are headed by grandmothers (Simmons & Dye, 2003; U. S. Bureau of the Census, 2003). In analyzing data from the National Survey of Families and Households (NSFH), Fuller-Thomson and colleagues (1997) found that 77% of the grandparents were grandmothers. Similarly, in a nationally representative longitudinal study in the U.S., Fuller-Thomson and Minkler (2000b) found that more than three-quarters (77%) of all caregiving grandparents were women. The ages of custodial grandparents have been reported to range between 35 and over 80 years, with the average age being in the mid 50's (Beverly, 1995; Minkler & Roe, 1993). However, nearly 20% of custodial grandparents in the U. S. are over the age of 65 (Fuller-Thomson & Minkler, 2000a; U. S. Bureau of the Census, 2003).

3.6. Consequences of Custodial Grandparenting

Positive Consequences

Despite the difficulties of assuming care of their grandchildren, grandparents report positive aspects of taking on this parental role. Grandparents receive pleasure from their close relationship with their grandchildren (Hayslip & Kaminski, 2005b) and feel intrinsically rewarded to care for a child (Giarrusso, Silverstein, & Feng, 2000). Caregiving can provide a meaningful new role for the grandparent leading to the grandparent feeling more useful and productive (Emick & Hayslip, 1999). Grandparents feel good that they are able simultaneously to help their adult child and their grandchild (Burton, 1992). The caregiving role may also afford grandmothers a second chance at successful parenting (Gatti & Musatti, 1999); grandmothers believe that they can learn from previous experiences and improve upon past negative parenting behaviors. In a study by Minkler and Roe (1993), grandmothers stated that the positive aspects of custodial grandparenting included knowing their grandchildren were safe and were being given a better chance to succeed. Grandmothers also were relieved and grateful at having the chance to do something positive for the family.

Negative Consequences

One of the main disadvantages of raising grandchildren is the risk of illness and/or disability for the caregiver. The normal declines in health related to aging may be exacerbated by the daily activities of caring for a child (Carr, Hayslip, & Gray, 2012; Hayslip & Hicks Patrick, 2006). Chronic health conditions may affect the grandparent's ability to perform those tasks associated with caregiving (Cox, 2003). Longitudinal data from the Health and Retirement Study (HRS) revealed that custodial grandparents were 80% more likely to report physical health problems and a decline in physical health over the previous year than were traditional grandparents (Hayslip, Temple, Shore, & Henderson, 2006). Minkler and Roe (1993) also found that 39% of grandparent caregivers reported deteriorating health after beginning to care for their grandchildren. However, grandparents often will deny their own health problems for fear of having their grandchildren removed from their care.

Another disadvantage of custodial caregiving is the risk of mental health problems resulting from the stresses of the caretaking role, aging, illness, socioeconomic status, and the grandchild's health (Carr et al., 2012; Kelley, Yorker, & Whitley, 1997). In a study by Kelley, Whitley, and Campos (2013a) of African American grandmothers raising grandchildren, almost 40% of the grandmothers showed clinically elevated psychological distress scores which were predicted not only by the grandchildren's behavior problems, but also by the physical health, family resources, and age of the grandmothers. Younger grandmothers and those with fewer family resources reported higher levels of distress. Conway, Jones, and Speakes-Lewis (2011) also found that among African American grandmothers raising their grandchildren, older grandmothers experienced less emotional and caregiving strain relative to younger grandmothers and that those who were married reported less emotional and caregiving strain. Other studies have shown that grandparents raising grandchildren have higher than expected rates of depression (DeToledo & Brown, 1995; Musil, 1998). In fact, results from one large national study showed that grandparent caregivers had close to twice the rates of depression of other grandparents (25.1% vs. 14.5%; Minkler, Fuller-Thomson, Miller, & Driver, 1997).

In addition to depression, grandparent caregivers may express various other feelings and emotions in regards to assuming custodial care. Feelings of shame, guilt, and anxiety over their own child's drug addiction, incarceration, or death are fairly common (Roe, Minkler, Saunders, & Thompson, 1996; Waldrop & Weber, 2001). Feelings of anger and resentment are also common as a result of assuming this unexpected and unwanted role (Minkler & Roe, 1993; Waldrop & Weber, 2001). Many experience grief over the various losses that have placed them in the caregiving role, especially the loss of their own child (Baird, 2003). As grandparents age, they must deal with the fear for their grandchild's well-being should they become unable to provide care due to physical or mental incapacitation or if they should die (Bullock, 2004; Shore & Hayslip, 1994).

Relationships with other family members and friends are affected when assuming care of grandchildren. In general, grandparents raising grandchildren have fewer and lower quality relationships than their peers who are not raising grandchildren (Solomon & Marx, 2000). Minkler, Roe, and Price (1992) found that grandmothers' marital relationships were negatively affected by the assumption of the caregiver role. Jendrek (1993) found that declines in marital satisfaction were four times more likely among grandparent caregivers than in two comparison groups of noncustodial grandparents. Decreased socialization with friends as a consequence of grandparent caregiving has also been observed (Jendrek, 1993, 1994; Minkler, Roe, &

Robertson-Berkeley, 1994). Shore and Hayslip (1990) found that almost 40% of custodial grandparents felt isolated from friends due to becoming caregivers. Feeling socially isolated was especially prominent if grandparents did not have any friends who were currently raising children (Bullock, 2004; Kelley et al., 1997; Strom & Strom, 2000). Consequently, custodial grandparents no longer “fit” into their traditional peer group or into the parent peer group of their grandchildren’s peers (Beverly, 1998).

3.7. Grandparents Raising Grandchildren with Disabilities

Grandparents raising grandchildren with disabilities often face unique challenges. The demands of assuming custodial care are exacerbated by raising a grandchild with physical, emotional, or behavioral difficulties or delays (Emick & Hayslip, 1999; Hayslip et al., 1998). Custodial grandparents are at greater risk for depression (Burnette, 2000; Janicki, McCallion, Grant-Griffin, & Kolomer, 2000) and experience more stress (Force, Botsford, Pisano, & Holbert, 2000; Grant, 2000), especially if they are dealing simultaneously with their own health issues (Burton, 1992) and the pressures of raising their grandchildren. Caring for grandchildren with developmental or other disabilities may increase the risk for symptoms of depression in grandparents. In a study of inner-city African American grandparents caring for at least one child with a developmental disability, Janicki and colleagues (2000) found that more than 50% of grandparents reported elevated symptoms of depression on the Center for Epidemiologic Studies Depression Scale (CES-D). Burnette (2000) found similarly high rates of depressive symptoms among inner city Latino grandparents of children with disabilities.

Because caring for a child with disabilities requires additional time and attention, grandparents’ feelings of burden and strain often are intensified (Hayslip et al., 1998; Sands & Goldberg-Glen, 2000). However, grandparents may under-report levels of emotional distress for fear of being viewed as incapable of raising grandchildren (Force et al., 2000; Janicki et al., 2000). Custodial grandchildren often have or are at risk of having physical, behavioral, and/or emotional problems stemming from circumstances that occurred prior to the grandparents assuming care. These circumstances include abuse or neglect by the biological parent, substance abuse by a parent, poor nutrition, inadequate cognitive stimulation in the early years, poverty, and inadequate health care (Ghuman, Weist, & Shafer, 1999; Janicki et al., 2000; Smith & Palmieri, 2007; Williamson, Softas-Nall, & Miller, 2003).

Children raised by grandparents experience higher levels of behavioral and emotional problems when compared to children living with their biological parents (Shakya, Usita, Eisenberg, Weston & Liles, 2012; Smith & Dannison, 2008). Silverstein and Vehvilainen (2000) found that 42% of the grandchildren in their study had special needs, including learning disabilities, ADHD, depression or developmental delays. In their investigation, Whitley and Kelley (2008) completed developmental screenings on young grandchildren of grandparents participating in an interdisciplinary intervention program. Those children with “suspect scores” on the screening instrument were given a full evaluation. Results of the study showed that nearly one-third of grandchildren had a diagnosis of fetal alcohol syndrome and another one-third of grandchildren had unspecified developmental delay. In a 2011 study, Kelley, Whitley, and Campos examined 230 children ages 2-16 years being raised by grandmothers and found 31.3% of the children scored in the clinically elevated range for total behavior problems. Of note, children of the grandmother caregivers who had increased psychological distress, fewer family resources, less social support, and less supportive home environments had increased behavior problems. Hayslip and colleagues (1998) examined the impact of raising grandchildren on custodial grandparents and found that about half of their sample of custodial grandparents reported caring for a grandchild with at least mild behavioral, emotional, school-related, or neurological problems. The disabilities and/or delays exhibited by custodial grandchildren often result in challenges for the grandparents who are striving to maintain family structure and function as effective caregivers (Smith & Dannison, 2002).

Hayslip and colleagues (1998) examined the impact of raising grandchildren with physical, emotional, or behavioral problems on custodial grandparents. Results showed that custodial grandparents had higher levels of personal distress than their peers raising grandchildren without significant problems. In a similar study, Emick and Hayslip (1999) found that grandparents raising grandchildren with neurological, physical, emotional, or behavioral problems exhibited the most distress, the most disruption of roles, and the most deteriorated grandparent-grandchild relationships. Researchers also report that custodial grandparents of grandchildren with mental retardation/developmental delay experienced greater stress and increased

depressive symptomatology than their peers whose grandchildren did not have mental retardation/developmental delay (Janicki et al., 2000; McCallion, Janicki, Grant-Griffin, & Kolomer, 2000).

Feelings of isolation can be compounded when grandparents must raise grandchildren with disabilities. For instance, children with behavioral, developmental, and/or physical disabilities often require specialized health care. Often, grandparents have no friends or family members who will provide assistance or respite care for the grandchildren with disabilities. The absence of regular and dependable respite has been reported as a major concern for grandparents who are isolated or who are facing the most demanding caregiving concerns (Burton, 1992; Minkler et al., 1992).

Evidence suggests that grandparent caregivers of children with disabilities experience both the same and heightened needs as other grandparent caregivers (McCallion, Janicki, & Kolomer, 2004). In a study involving grandparent families with and without children with disabilities, McCallion and colleagues (2000) found that grandparents caring for a child with a disability received less social support than did other family caregivers. Grandparents also reported experiencing higher levels of role strain, financial strain, and life disruption than either custodial grandparents raising grandchildren without problems or traditional grandparents (Emick & Hayslip, 1999). Findings from a study examining the perceived needs of grandmothers of children with disabilities confirmed that these grandmothers had unique needs including informational needs, respite needs, and needs for strategies to deal with issues related to their grandchild's disability (Gallagher, Kresak, & Rhodes, 2010).

3.8. Sources of Support

Families need both formal and informal resources and support in order to handle the day-to-day activities of family life. Often, social support is found to be a mediator of stress in parents (Hayslip & Hicks Patrick, 2006) and may serve the same role for grandparents. Thus it is important to examine sources of both informal and formal supports for grandparents raising grandchildren. Formal support is described as professionally delivered, specific, social services which are available to custodial grandparents in order to meet their instrumental or emotional needs (Musil et al., 2000). Informal support often comes from family, friends, neighbors, or religious organizations and includes both instrumental and emotional support. Both types of social support refer to individuals having or feeling a sense of assistance (Landry-Meyer, Gerard, & Guzell, 2005).

In assuming a parenting role, grandparents may find themselves isolated as a result of their new responsibilities. Established support networks may be disrupted due to the assumption of the parental role, thus making grandparents vulnerable to stress (Cox, 2003; Minkler et al., 1994). The number, age, and gender of grandchildren as well as any behavioral and/or health problems the grandchildren have may increase the need for social support (Hayslip & Hicks Patrick, 2006). Whitley and colleagues (2001) found that without support to help with daily routines, grandmothers had difficulty in meeting the physical demands of parenting on a long-term basis. Consequently, inadequate social support and social isolation can affect the physical and mental health of custodial grandparents, as well as their parenting ability due to increased psychological distress (Fuller-Thomson & Minkler, 2000b; Kelley, Whitley, Sipe, & Yorker, 2000; Solomon & Marx, 2000), placing custodial grandparents at risk for depression (Musil, 1998) and lowered self-esteem (Giarrusso, Silverstein et al., 2000).

On the other hand, adequate social support can mitigate the effects of the numerous stressors custodial grandparents face (Giarrusso, Feng, Silverstein, & Marengo, 2000; Hayslip & Shore, 2000; Kolomer, McCallion, & Overeynder, 2003). Through collaborative efforts, grandparents and professionals can efficiently locate and manage the varied resources, supports, and services required by the family which would likely improve the family's quality of life (Dunst & Bruder, 2002). Researchers have found that increased levels of emotional (e.g., friendships, empathy) and instrumental (e.g., respite, child care) support have been associated with less depression, less parental role strain, and better self-rated health among custodial grandmothers (Emick & Hayslip, 1999; Musil & Ahn, 1997). Indeed, Emick and Hayslip (1999) found that well-being was related to overall social support from one's children and from one's friends whereas more effective parental coping was associated with support from relatives. In a similar study, Hayslip and colleagues (1998) found that among grandparents raising grandchildren with neurological, physical, emotional, or behavioral problems, more overall social support and more support provided by the grandparents' own children were associated with increased tolerance of a grandchild's disruptive or irritating behavior.

Often, accessing formal and informal support is difficult for custodial grandparents. Many grandparents may not have access to social services which are currently available to them. Minkler and colleagues (1993) identified lack of transportation and suitable child care as two barriers to accessing community interventions among grandparent caregivers. Grandparents of school-aged children frequently mentioned issues and challenges regarding the grandchild's school as an area of concern (Shakya et al., 2012). Hayslip and Shore (2000) discovered that many grandparents do not use formal services because they lack awareness of available services, lack time or transportation, cannot afford the expense of such help, or require more specialized services. Even if grandparents are aware of available services, they may avoid seeking assistance due to the stigma associated with the reasons for becoming custodial grandparents in the first place (Fuller-Thomson & Minkler, 2000a; Porterfield, Dressel, & Barnhill, 2000) or for fear of being perceived as incompetent caregivers (Gerard, Landry-Meyer, & Roe, 2006).

When grandparents assume caregiving responsibilities, there are changes in their informal social supports, which can affect the support they receive. A large social network does not necessarily guarantee that grandparents will receive assistance or support. Indeed, Burton (1992) found that 97% of the grandparents and great grandparents in her study did not receive consistent and reliable support from family members. Grandparents often report losing friends when they take on the parenting role because their friends are no longer raising children of their own (Wohl, Lahner, & Jooste, 2003). Finding support and friendship among active parents may be difficult due to the age difference between custodial grandparents and traditional parents who are often much younger. A highly demanding or troubled grandchild might lead some friends or family members to avoid the grandparent. Likewise, grandparents who experience high amounts of daily parenting hassles may rely too heavily on particular friends or family, thus exhausting their resources (Gerard et al., 2006).

Where a family resides can influence the support and services they receive. Grandparents in rural areas may encounter unmet needs due to fewer available resources, ill-equipped social service agencies, transportation concerns, and geographic isolation (Cohen & Pyle, 2000; Cuellar & Butts, 1999). Grandparents in rural areas may experience more social isolation than grandparents in urban areas due to the remote geography and the greater physical distance between neighboring families (Roberto, Richter, Bottenberg, & MacCormack, 1992). However, in their study examining the needs and supports of caregivers of young children with disabilities, Darling and Gallagher (2004) found evidence to the contrary. Urban caregivers reported receiving less overall support and feeling more isolated than their rural counterparts, despite living in a more densely populated area. Even though it may be assumed that grandparents living in urban areas may have more access to supports, this may not always be the case.

In addition to formal and informal support, the perception of social support plays an important role in how grandparents handle the stressors of raising grandchildren. Perceived social support is defined as an individual's appraisal of the availability and adequacy of one's social support network (Gerard et al., 2006; Landry-Meyer et al., 2005). Research has documented that the nature and amount of perceived support from both formal and informal sources correlate highly with successful coping (Dunst, Trivette, & Deal, 1994). Musil (1998) found that greater perceived support was associated with less depression in custodial grandparents. On a similar note, Giarrusso, Feng, and colleagues (2000) found that greater perceived support lessened the negative effect of stress on the self-esteem among custodial grandparents. However, grandparents' estimates of the support they receive from others or from formal social services agencies may differ from the actual degree of support offered (Kolomer et al., 2003; Landry-Meyer, 1999). Few grandparents perceive themselves as receiving reliable support from families and friends necessary to fulfill their familial obligations even though they may be part of a large informal network (Burton, 1992; Minkler & Roe, 1993). Grandparents in the Shakya et al. (2012) study reported challenges utilizing social supports, with 44% reporting they had no one to whom they could turn for emotional help. Appraisals of low social support from significant others can undermine grandparents' well-being, especially when paired with the demands of their grandchildren's problems and the everyday hassles of caregiving (Kolomer et al., 2003).

In summary, research has shown that social support has direct, mediational, and moderating influences on the behavior and development of children with disabilities (Bruder, 2000). A recent study by Whitley, Kelley, and Campos (2011) found that African American grandmothers who participated in a strengths-based intervention for one year experienced an increase in perceived empowerment, with younger grandmothers having a greater sense of empowerment and competency than did older grandmothers. Informal support, in particular, has shown the strongest relationship to both family and child outcomes. However, grandparents caring for a child with a disability report receiving less support than either custodial grandparents raising

children without problems or grandparents who are not raising grandchildren, thus placing the families at risk for negative outcomes (Baker, 2000; Emick & Hayslip, 1999; McCallion et al., 2000).

3.9. Family Quality of Life

Another important aspect of family outcomes is family quality of life. Though there can be many positive aspects of raising a child with disabilities, families of children with disabilities are also often confronted with ongoing challenges that can impact various aspects of family life (Lecavalier, Leone, & Wiltz, 2006; Werner et al., 2009). These challenges have been associated with increased feelings of burden, stress, depressive symptoms, and lower levels of family well-being (Baker et al., 2003). Researchers have expressed an interest in a more global construct to reflect family well-being, namely family quality of life (Brown, MacAdam-Crisp, Wang, & Iarocci, 2006; Brown, Neikrug, & Brown, 2000; Poston et al., 2003). Family quality of life has been defined as “conditions where the family’s needs are met, and family members enjoy their life together as a family and have a chance to do things which are important to them” (Park et al., 2003; p. 368). Based on a survey exploring valued outcomes, Dunst and Bruder (2002) reported that family satisfaction and improved family quality of life were the most valued outcomes determined by practitioners and parents. Therefore, leaders in the disability field have called for family quality of life as a valued outcome of policies and services (Bailey et al., 1998, Dunst & Bruder, 2002; Turnbull, Brown, & Turnbull, 2004); this quality of life issue extends to grandparent-headed families. Family quality of life extends beyond the individual with a disability and encompasses the needs of all family members, including grandparents (Smith-Bird & Turnbull, 2005; Zuna, Turnbull, & Summers, 2009).

Research has shown that higher levels of depression and stress are negatively associated with family quality of life (Baker et al., 2003; Zuna, Summers, Turnbull, Hu, & Xu, 2009). Because custodial grandparents are at risk for both stress and depression and are more likely to be raising a child with a disability, it is important that custodial grandparents and their families receive the supports they need in order to improve their quality of life. Neely-Barnes, Graff, and Washington (2010) looked at the health-related quality of life of custodial grandparents and found that grandparents with a good quality of life were significantly more likely to report that they had enough help and support than those in the fair or poor groups. These grandparents were also significantly less likely to report that their grandchildren had emotional, behavioral, or health problems.

Providing family support and delivering services using a family-centered approach are established core concepts of disability policy and practice (Turnbull, Beegle, & Stowe, 2001). Family supports and services should be targeted on ameliorating negative while strengthening positive impacts of raising a grandchild with disabilities (Summers et al., 2005). By examining family quality of life, professionals may be better able to identify possible challenges which families face, especially grandparents raising grandchildren, and the supports necessary for them to have true quality of life (Purcell, Turnbull, & Jackson, 2006).

4. Summary and Implications

Families have a powerful impact on their children’s development. As the definition of a family continues to expand beyond biological parents, researchers and practitioners must also broaden their views of what constitutes a family; such a broadened view must include grandparents as primary caregivers of children with, and without, disabilities. Since grandparent caregiving has been linked to negative outcomes such as decreased peer-network interaction and social isolation, depression, and lowered life satisfaction (Burton, 1992; Fuller-Thomson & Minkler, 2000b; Kelley et al., 2000), it is important to identify social support resources that may facilitate positive development among grandparent caregivers (Landry-Meyer et al., 2005). The availability of adequate social support may be an important factor in contributing to the success of grandparent-headed households (Hayslip, King, & Jooste, 2008). As more grandparents assume the parental role, they will need greater support from community services, educators, practitioners, and clinicians to assist them in providing for their grandchildren and to help them cope with the physical and emotional challenges brought on by an altered family life (Roberto & Qualls, 2003). Understanding the specific social support needs of grandparents raising grandchildren will be particularly important for the development of public policy advocating for grandparent caregivers and their grandchildren (King, Hayslip, & Kaminski, 2006).

Results of this review point to the need for societal support for grandparents raising grandchildren, especially those raising grandchildren with disabilities. Strengthening grandparents’ social support (both

formal and informal) and family resources, as well as promoting their knowledge and skills regarding family competence are essential to increasing family quality of life, which can lead to more positive family and child outcomes. Researchers (Campbell & Miles, 2008; Kelley, Whitley, & Sipe, 2007; Kelley, Yorker, Whitley, & Sipe, 2001) suggest using a strengths-based case management and group support services approach to build on the strengths which grandparents already have. Interventions to caregiving grandmothers, such as those by Kelley, Whitley, and Campos (2010, 2013b), combined home-based visitation by nurses and social workers, along with support groups and parenting classes. Such support groups can be beneficial to grandchildren as well since they help promote a more nurturing environment for the grandchildren. Grandparents who have used support groups report the groups are useful to obtain information about available services, and as a means to share concerns about their current situation, as well as to reduce feelings of isolation (Cox, 2003; McCallion et al., 2004; Strom & Strom, 2000). When grandparents are raising grandchildren with disabilities however, they find it harder to attend such support groups as they usually have few resources available for child care. In fact, Emick and Hayslip (1999) found that over 50% of the grandparents raising grandchildren with developmental problems in their sample had not gone to any type of support program. It is important to broaden our efforts in providing support to grandparents raising grandchildren with disabilities.

Most of the intervention approaches used with grandparents raising grandchildren with disabilities have been geared toward strengthening the grandparent's skills in managing the behaviors of the grandchildren and/or providing emotional support for the grandparents (Thomas, Sperry, & Yarbrough, 2000). Using family-centered help-giving practices may help families build and use informal support systems. Likewise, professionals can provide services that are individualized and supportive by recognizing the family's prior history and focusing on their unique strengths (Smith & Dannison, 2008). If families feel confident in their abilities to handle everyday life without constant support, they may experience increased opportunities for positive family functioning, thus increasing their satisfaction with family quality of life.

Intervention approaches must take into account the unique needs of the diverse groups of grandparents raising grandchildren. It is important to recognize the circumstances that formed the family, the cultural values and norms of the family, the family supports, and the family's unique stressors, as well as the fact that grandparents may be raising one or more grandchildren with disabilities. Such recognition is critical to the design and implementation of both informal and formal supports for grandparents raising grandchildren. Understanding the specific social support needs of these grandparents may help in the development of public policy advocating for grandparent caregivers and their grandchildren (King et al., 2006).

4.1. Suggestions for Future Research

Based on the findings of this review, there are several suggestions for future research. The major one is to encourage research in the area of custodial grandparents raising grandchildren with disabilities across different countries. Many of the reviewed studies were conducted in the U.S., and many were conducted over 10 years ago. Carefully looking at the sources of support and family quality of life of grandparents raising grandchildren with and without disabilities across countries is important since cultural and religious values will necessarily play into the results. Research should look at the perspectives of both grandmothers and grandfathers. Most of the literature has focused exclusively on grandmothers' perspectives and it is important also to look at grandfathers since different family members may access varying sources of support. It would be helpful to look longitudinally at what it is like for grandparents to raise grandchildren, both with and without disabilities, since the regular family literature suggests changes over time as children age. Likewise, it would be helpful to conduct research on grandparents raising grandchildren in urban areas vs. rural areas, since sources of support typically vary across geographic areas. Grandparents assume care of their grandchildren from diverse and unpredictable circumstances such as substance abuse, incarceration, neglect, or the death of a parent. Currently, there may be even more grandparents helping with the care of their grandchildren due to recent stressful economic situations across the globe. These differing circumstances can put the grandparents at risk for psychological distress and most likely affect their well-being. For example, Ross and Aday (2006) found that grandparents in the U. S. whose reason for caregiving was because of neglect related to parental substance abuse had lower levels of stress while grandparents whose reason was because of the death of the grandchildren's parent(s) experienced more stress. It would be beneficial to professionals to know the effect of the reason for the assumption of care in order to provide the appropriate support and services needed by the grandparents.

For grandparents raising grandchildren with disabilities, research studies that incorporate a wide range of disabilities is another area of future research. The special needs of the grandchildren often determine the nature of the child-rearing stresses experienced by the grandparents (Kelley, 1993). Some disabilities may require specialized health care making childrearing even more demanding for the grandparents. The extra demands placed on grandparents for nurturing and support have been associated with higher levels of stress (Burton, 1992). The complex needs of grandchildren with disabilities may compromise the grandparent's ability to parent effectively and be a source of ongoing stress (Campbell & Miles, 2008; Grant, 2000); thus more research is needed in this area.

In summary, grandparents raising grandchildren has become a common phenomenon across the globe. This reconfiguration of the family is diverse and has occurred across every socioeconomic and ethnic group (Fuller-Thomson et al., 1997; Minkler & Roe, 1993). As a result, many grandparents are experiencing increased psychological distress. One of the most well documented contributors to this distress has been social isolation (Dowdell, 1995; Minkler & Roe, 1993). The availability of social support, both formal and informal, has been shown to have a powerful impact on grandparents' emotional health and well-being (Davis & Gavidia-Payne, 2009; Gerard et al., 2006; Giarrusso, Silverstein et al., 2000), thereby influencing family functioning. A family's social networks, which can include a mix of intrafamily, informal, community, and formal social network members, are an essential component for positive family functioning (Dunst, 2000). Through family support services, professionals can promote the families' abilities to obtain and mobilize resources and strengthen their support networks. Strengthening grandparents' support networks, especially for those grandparents raising grandchildren with disabilities, could have a positive effect on family quality of life, specifically, and positive child and family outcomes, in general.

4.2. Implications

Educators must be cognizant of the differences in grandparents' understanding of current educational systems (Strom, Heeder, & Strom, 2005). Curricula and school environments could have changed compared to when their own children attended, especially if the grandparent is much older. Therefore, grandparents may need assistance in understanding the new materials and expectations required to support learning in the classroom. In addition, grandparents raising grandchildren with disabilities may be unfamiliar with the special education process and procedures for obtaining services for their grandchildren. They may require information pertaining to the child's disability as well as assistance in obtaining the needed services.

Preparing educators to work with diverse family systems should be an essential element of teacher preparation programs. Educators may not fully understand the challenges and struggles of raising grandchildren, especially those with disabilities. By providing a grandparent-friendly atmosphere within the school and classroom, educators can work to build good relationships with the families, thus promoting positive student outcomes.

It is important to recognize that grandparents, especially those raising grandchildren with disabilities, may not be able to participate in school activities due to poor health, lack of transportation, absence of childcare or limited time. Educators need to realize that grandparents can participate in what Fields-Smith (2008) refers to as "invisible forms of involvement" (p. 161), which can both directly or indirectly contribute to the grandchild's learning. This type of involvement may include reading together, working on projects, preparing materials for classroom instruction, or coordinating activities for classroom events. By allowing grandparents to participate in various ways, educators send the message that grandparents' involvement is valued and essential to the success of their grandchildren.

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