AN EXAMINATION OF INSTRUMENTAL SUPPORT RECEIVED BY PARENTS OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS THROUGHOUT THE LIFE COURSE

A thesis submitted to the Kent State University College of Education, Health, and Human Services in partial fulfillment of the requirements for the degree of Master of Arts

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The purpose of this study was to gain a deeper understanding of the instrumental support received by parents of children with special health care needs (CSHCN) throughout the life course. The study sample included 489 parents of CSHCN obtained from the Wave III sample and the Refresher sample of the Midlife Development in the United States (MIDUS) survey. The study provided a description of the sources of unpaid assistance for the parents of CSHCN and yielded significant findings regarding variations in support receipt associated with life course variables.

Parents receive significantly more instrumental support from informal sources than from formal sources at each stage of the family life cycle. Additionally, a significant positive relationship exists between the amount of support received from formal sources and the amount of support received from informal sources. The receipt of support from various specific sources also demonstrates a relationship with the receipt of support from other specific sources. Finally, life course variables including religious participation and gender were associated with the receipt of support from formal sources, whereas family life cycle stage was associated with the receipt of support from informal
Parents from families with young children reported receiving significantly more unpaid assistance from informal sources than parents from families at all other life cycle stages. These findings help inform service providers as to parents who may potentially need assistance securing instrumental support as well as point to potential areas for future research.
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CHAPTER I

INTRODUCTION

It is estimated that 15.1% of children in the United States have a chronic condition or disability which requires special health care (National Survey of Children with Special Health Care Needs, 2009/2010). The family of a child with special health care needs may face increased physical and psychological demands in providing treatment regimens, coordinating care, worrying about health outcomes, and paying for potentially expensive medical care. These demands can place the child’s parents at increased risk of diminished health-related quality of life (Van Nimwegen et al., 2016), elevated stress (Cousino & Hazen, 2009; Pedersen, Parsons, & Dewey, 2004), increased anxiety (Streisand et al., 2008), elevated depressive symptoms (Driscoll et al., 2010; Streisand et al., 2008), and burnout (Lindström, Aman, & Norberg, 2010). Subsequently, the entire family system is at risk for maladjustment and negative outcomes.

How parents cope with caring for a child with special health care needs can set the family system on a course of either resilience or crisis. Resilient families are able to effectively cope with the challenges presented by a child’s special health care needs, successfully adapting to a new, and even sometimes improved, normal (Walsh, 2016). They find purpose in the existence of the child’s health condition and, rather than experiencing deterioration within the family system, they experience strengthened relationships and family functioning.
A family resilience framework (Walsh, 2016) identifies the resources a family has available as a key element for successful adaptation. One resource repeatedly identified as an essential component of family resilience is social support (Walsh, 2016). As Hobfoll and Spielberger (1992) emphasize, “Whether from family, colleagues, or friends, social support is the major vehicle for the provision of resources outside of the self” (p. 104). Social support has been defined broadly in the literature as any type of aid provided to an individual (Hobfoll & Lerman, 1989). As resilience is not a one-time status that a family achieves but rather a set of processes and growth experienced over time, examining resilience and the resources that promote resilience through the lens of life course theory seems only natural. Using a life course perspective, this study will examine the sources of instrumental support received by parents of a child with special health care needs (CSHCN) and the family life cycle stage, family structure, and parent demographic variables associated with the sources of instrumental support received by the parents, with an underlying assumption that the social support received promotes family resilience (Walsh, 2016).

Effects of Social Support on Families of CSHCN

The various dimensions of social support have been shown repeatedly to serve as a resource for the families of children with special health care needs through the effect on parental outcomes. A study by Lovell and colleagues (2012) found that parents who perceive greater social resources appraise their caregiver role as less stressful, have more adaptive functioning of the hypothalamic-pituitary-adrenal axis (HPA; Lovell, Moss, &
The HPA axis is responsible for controlling the body’s stress reactions and helps regulate a number of the bodily processes.) They also experience fewer maladaptive physical and psychological symptoms than those perceiving fewer social resources. Social support has also been shown to be a correlate of maternal adjustment (Dewey & Crawford, 2007), maternal adaptation (Weiss, 2002), and levels of parenting stress (Pedersen, Parsons, & Dewey, 2004). The size of the social support network has been shown to serve as a buffer against longer-term global psychological distress (Harper, Peterson, Albrecht, Taub, Phipps, & Penner, 2016) and to be associated with improvements in maternal well-being (Smith, Greenberg, & Seltzer, 2012).

Improved parental outcomes can also benefit the family by enhancing a child’s health and behavioral outcomes. Research on social support for parents has demonstrated an indirect association with an adolescent child’s improved diabetes illness management behavior (Carcone et al., 2011) and a potential buffering effect on a child’s asthma symptoms (Conn et al., 2015). Additional research has shown a relationship between a parent’s balance of social support and stress with behavioral outcomes in their child with cerebral palsy (Sipal et al., 2009). With this body of evidence, the current study is performed upon the premise that social support, specifically instrumental support, is beneficial in promoting resilience for the families of children with special health care needs.

Still, inconsistencies as to how to conceptualize and measure social support exist in the literature. Cohen and Wills (1985) contend that social support can be examined by
both its structure (sources of support) and its function (type of support provided). Both structure (Horton & Wallander, 2002; Smith, Greeberg, & Seltzer, 2012) and function (Guralnick, Hammond, Neville, & Connor, 2008) have demonstrated effects on the well-being of parents of CSHCN. Cohen and Wills found that measures of social network integration (structure) have a main effect of promoting well-being and stability, whereas the function (type) of support provides a buffering effect in the presence of elevated stress. Additional research describes the concept of enacted support (Barrera, 1986) that is similar to Cohen and Wills’ concept of functional support, as it is the form of tangible support that is likely to be provided during times of adversity. Because enacted support is likely to be provided during stressful events, the current study focuses exclusively on enacted (or functional support). Cohen and Wills (1985) also identify dimensions of functional (enacted) support: emotional support, informational support, social companionship, and instrumental support. Though functional support can be measured within any domain or globally (Barrera, 1986), this study will specifically examine instrumental support because of its importance within the context of families with a CSHCN.

Instrumental support can be conceptualized as the provision of resources which can entail financial support, material resources, or support in performing tasks like child care or household chores (Cohen & Wills, 1985). For the present study, instrumental support will be conceptualized as hours of unpaid assistance received in the past month. Paid assistance will not be considered, in order to ensure that comparisons are less
confounded. Gaining insights into instrumental support received by the parents of CSHCN will be informative for professionals working with this population.

According to the 2009/2010 Survey of Children with Special Health Care Needs, 13% \((n=4,271)\) of families indicated spending 11 or more hours per week providing and/or coordinating care for their child’s health care needs. Over 6% \((n=2,625)\) of families of CSHCN indicate the need for more family support services in the form of respite care, and of those families, over 49% \((n=1,321)\) feel the need for respite care is not currently being met (National Survey of Children with Special Health Care Needs, 2009/2010). Respite care was explained as having someone care for the child with the special health care need so the caregiver can do other things. This need for respite care does not encompass the full extent of instrumental support needs a family of a CSHCN may have. With the amount of time spent coordinating and providing care for the CSHCN, it can be expected that there are needs for assistance with other tasks like household chores, transportation, and childcare for other children in the household.

These needs for instrumental support may be met by informal sources of social support as well as formal sources of social support. *Informal sources of social support* to be examined in this study include the respondent’s parents, parents in-law, grown children or grandchildren, and other family and friends. *Formal sources of social support* to be examined include community volunteers, religious groups, private organizations, and government agencies. It is the aim of the study to identify specific sources of both informal and formal instrumental support.
Sources of Social Support for Parents of CSHCN

Existing research, to a limited extent, examines the sources of social support received by parents of children with special health care needs, usually as only a small part of larger research objectives. Fathers have indicated extended family, community, church, and the workplace as sources of support (Brody & Simmons, 2007). Family members, including spouses, parents, and children have been cited as the primary source of social support for parents (Patterson, Garwick, Bennett, & Blum, 1997; Pfeifer et al., 2013). With few exceptions, the majority of studies reviewed utilize global support measures, making it difficult to distinguish the function of support reported by the parents. A 2002 study by Weiss compared hardiness and social support as predictors of stress in mothers of children with autism, mothers of children with intellectual disabilities, and mothers of typical children. The study utilized measures of informal perceived support, informal functional support, informal support within the marriage relationship, and access to formal support services. However, only correlation and predictive ability were reported, leaving the quantity of support from the different domains (formal, informal, perceived, and functional) and different sources unexplored. This is the case for much of the literature examining social support for families of CSHCN. It is important though, not only to understand the type of support received, but also from where the support comes and how much support comes from each source. Knowing the source and amount of support received from each source can help
researchers begin to understand if it is the type of support, the source of support, or the amount of support that is most salient for promoting family resilience.

**A Life Course Framework**

This study incorporates a life course framework to examine how social support for parents of CSHCN varies across the course of the family life cycle. “The life course perspective involves a contextual, processual, and dynamic approach to the study of change in the lives of individual family members over time, and of families as social units as they change over historical periods” (Bengston & Allen, 1993, p. 469). Two central notions of a life course perspective that may shape the social support received by the parents of CSHCN are the *timing of lives* and *linked lives*. The timing of lives refers to the incidence, duration, and sequence of roles and relevant expectations and beliefs based on age. Some events are timely in relation to age norms, whereas some may be ill-timed (Elder, 1994). At the microsocial level, the timing of lives can be seen in family life cycle stages. Family life cycle stages are patterned stages defined by family composition and transitions that affect the behavior of individual members over time (Bengston & Allen, 1993). Accordingly, we can expect that the impact of a child’s health care need and the social support needed will vary depending on which stage in the life cycle the family occupies and whether that stage is normative or non-normative. Duvall and Miller (1985) conceptualized eight stages in the family life cycle, with each stage associated with specific developmental tasks. Those eight stages include: the establishment phase, families with infants, families with preschool children, families with
school-aged children, families with adolescents, families with young adults, the middle years, and aging family members (Smith & Hamon, 2012). As developmental tasks change with each life cycle stage, we can expect support needs and sources to vary across those stages. For example, a mother with preschool children may use more instrumental support from her parents as she copes with the energy demands required to stimulate and promote the development of her busy, young children, whereas an aging mother entering retirement may have less need for instrumental support, but may need to obtain any instrumental support she needs from her grown children.

According to Elder (1994), linked lives is the most central notion of life course study. Personal stressors like the disability or chronic illness of a child are intergenerational in nature due to the fact that our lives are embedded in social relationships across the life span. The concept of linked lives, therefore, is how an individual’s social worlds interact over the life span (Elder, 1994). For instance, a child’s special health care need will affect not only his or her own life, but the lives of the child’s parents, grandparents, siblings, children, and the social relationships and support networks within the whole family system.

Recent demographic shifts in family structure necessitate examining associated life course variables indicative of the timing of lives and linked lives. Among those shifts, increases in life expectancy, changes in fertility timing and rates, patterns of divorce and remarriage, and age upon entering grandparenthood result in diversity of
family life cycle stages and family structures (i.e., family composition and family size; Bengston & Allen, 1993).

**Social Support, Life Course, and Families**

Examining the social network of families with a CSHCN from a life course perspective, we can hypothesize that both the family life cycle stage and the family structure will influence the social network and subsequent support available to the parents. Because of the notion of linked lives, for example, we can expect that as the parents of a CSHCN enter later life, the amount and function of support the child’s grandparents are able to provide to the parents will change as well. This is consistent with Kahn and Antonucci’s (1980) explanation of convoys over the life course. A convoy consists of those people who are important to an individual specifically in terms of social support. According to Kahn and Antonucci, there should be observable changes in an individual’s convoy and patterns of social support throughout the life course. For example, network members associated with a parent’s roles should be particularly prone to falling out of the convoy as parents transition out of those roles (i.e., the loss of coworkers from a parent’s convoy when the parent enters retirement). Transitions such as retirement that usually occur as a normal part of the family life cycle may have a different impact on the convoy of single-parent families, multigenerational households, and families with adult children still at home, thus it is important that the effect of family structure also be examined.
Limited prior research has examined how the sources of social support may change throughout the life course for parents of a child with special health care needs. However, the need for such research assessing the social support process for families of CSHCN over time has been stated (Krahn, 1993). More recently, Smith, Greenberg, and Seltzer (2012) noted the need for further research to examine how social support may change over time for the parents of children with Autism Spectrum Disorder (ASD).

Again, in their 2016 article on the effects of social support on psychological distress in parents of pediatric cancer patients, Harper and colleagues suggest the need for research studying how social support changes over time (Harper et al., 2016), as those changes have implications for the psychological adjustment of the child’s parents.

This study will attempt to fill the gap in existing research by specifically examining variables related to the life course notions of timing of lives and linked lives. Kahn and Antonucci (1980) note the importance of transitions and role changes throughout the life course in changing the shape of one’s convoy. For a family, key transitions and role changes revolve around family life cycle stages.

**Statement of the Problem**

Research specifically examining the nature of the support sources of families of children with special health care needs is lacking. Caring for a CSHCN can present a challenge to healthy family functioning, as emotional and physical resources are taxed. Families, however, are capable of displaying resilience in light of this challenge. Informal and formal support networks are crucial to facilitating family resilience. Thus,
it is critical that we gain a deeper understanding of the support sources utilized by families of CSHCN. Since the impact of a child’s special health care needs, the parent’s support needs, and the structure of a family’s support network evolve over time, it is also important that sources of support be examined through a life course perspective. Though empirical studies since 2010 have specifically examined the effects of social support for families of CSHCN (Carcone et al., 2011; Ekas, Lickenbrock, & Whitman, 2010; Fonseca, Nazaré, & Canavarro, 2014; Harper et al., 2016; Lovell, Moss, & Wetherell, 2012; Magliano et al., 2014; Pfeifer et al., 2013; Smith, Greenberg, & Seltzer, 2012), no recent studies were identified in this review of the literature that examine the sources of instrumental support received by parents and how that support may evolve throughout the life course for families with a CSHCN. A qualitative study by Mah and Biggar (2012) did examine the psychosocial support needed by parents of boys with Duchenne Muscular Dystrophy and found that the types of support needed varied across the stage of the illness and family situation. In order to enhance family resilience, it is important that research turn its attention to identifying the specific sources of instrumental support received by parents of children with all types of special health care needs as well as how support received by parents varies by life course variables, including family life cycle stage and family structure. This information could provide service providers with knowledge of parents who may be at risk of adverse effects due to having limited sources and/or amounts of instrumental support.
Study Objectives

Given the lack of current research, my goal is to lay the groundwork for future research on the evolution of social support received by parents of children with special health care needs throughout the family life cycle. Examining families through a life course perspective, I expect that the sources from which a parent receives social support will vary based on the family’s life cycle stage and based on the family structure.

Accordingly, five objectives will guide this study:

1. To examine the amount of instrumental support parents of CSHCN receive from specific sources of informal (i.e., parents, in-laws, adult children, and other family/friends) and formal (i.e., volunteers, religious groups, private organization, and government agency) support.

2. To identify associations between the amount of instrumental support received by parents of CSHCN from informal sources and the amount of instrumental support received from formal sources.

3. To identify how the total amount of instrumental support received by the parents of CSHCN and the amount of instrumental support received from specific informal and formal sources vary by parental demographic variables.

4. To identify how the total amount of instrumental support received by the parents of CSHCN and the amount of instrumental support received from specific informal and formal sources vary by family structure variables.
5. To identify how the total amount of instrumental support received by the parents of CSHCN and the amount of instrumental support received from specific informal and formal sources vary by family life cycle stage variables.

The intent of this study is to help identify families potentially at risk of poor family functioning due to receiving relatively less formal and/or informal instrumental support as well as to identify members of the parents’ convoy who may experience excess burden in providing instrumental support to the parents of CSHCN. This will subsequently inform health care and social service providers as to opportunities for expanded programs of instrumental support provision to vulnerable families of CSHCN as well as vulnerable members of the family’s convoys. It will also inform families of children with special health care needs as to potential shifts in sources of support as they travel through the family life cycle. Efforts can then be made to bridge the gap between parents and the social support needed to enhance family resilience.
CHAPTER II
LITERATURE REVIEW

In an effort to support the need for research into the sources of instrumental support received over the life course by parents of children with a special health care need (CSHCN), I will first demonstrate the family impact of having a CSHCN, then review the literature on the effects, mechanisms, and sources of social support for families of a CSHCN, and finally examine the literature on social support over the life course for families of CSHCN. I will conclude by presenting hypotheses for the present study.

Family Impact of a Child with Special Health Care Needs

The families of children with special health care needs face the same stressors as families of healthy children and also additional stressors specific to having a CSHCN. Those stressors can include financial strains, strains on family functioning, a decrease in family privacy and activities, caregiving stresses, concern/worry for the child’s health, and problems with service providers (Cohen, 1999; Patterson & Leonard, 1994).

According to the National Survey of Children’s Health, of the more than 11,000,000 CSHCN, the condition causes financial problems for 21.6% of families, 13.1% of families spend 11 or more hours per week providing or coordinating their child’s health care, and in 25% of families, the condition causes one or more family member to cut back hours or quit working entirely (NSCH, 2009/2010). These added stressors can take a toll on both individual well-being and family functioning. Though research is beginning to
examine the impact a child’s special health care need has on all members of the family system, (i.e., siblings), for the purpose of the present study, the focus will be on the impact on parental well-being and general family functioning.

**The Impact of CSHCN on Parental Well-being and Family Functioning**

Having a child with a special health care need can impact the mental, emotional, and physical well-being of the parents. Parents of CSHCN have been found to experience more parenting stress than parents of healthy children (Cousino & Hazen, 2013; Pedersen, Parsons, & Dewey, 2004). They are more prone to burnout than the parents of healthy children (Lindström, Aman, & Norberg, 2010). Parents of a CSHCN have been found to experience increased anxiety (Streisand et al., 2008) and elevated depressive symptoms (Driscoll et al., 2010; Streisand et al., 2010). Parenting a CSHCN is also negatively associated with a parent’s health-related quality of life (Davis et al., 2009) and overall quality of life (van Nimwegen et al., 2016). Parental quality of life seems to be associated with the severity of the child’s condition, with parental quality of life decreasing as condition severity increases (Boling, 2005).

As a consequence of poor psychological adjustment in parents, the family may be at greater risk of experiencing family level stress (Driscoll et al., 2010) and other negative outcomes. Parents of a CSHCN may also be more prone to marital discord (Cohen, 1999) and divorce than the parents of healthy children, and the pattern of divorce over the life course may vary from parents of healthy children (Hartley et al., 2010). Hartley and colleagues (2010) examined the occurrence and timing of divorce among parents of
adolescent and adult children with autism spectrum disorders (ASD) and found that the risk of divorce was nearly twice that for a comparison group of parents. Further, unlike the comparison group, the rate of divorce for parents of a child with ASD remained steep through the child’s adolescence and early adulthood. These findings may be more unique to parents of children with ASD or other developmental disorders rather than generalizable to children with medical conditions. A 2010 study by Syse and colleagues revealed conflicting results for rates of divorce among the parents of CSHCN. They found that having a child with cancer was not associated with an increased risk of divorce, however, there was an increased risk of divorce in the parents of children with Wilms tumors. This points to the role the nature of the child’s health condition plays with regard to family outcomes.

**Individual and family variables as risk factors for poor outcomes.** Individual and family variables have been found to be associated with outcomes for parents of CSHCN, including parental age (Smith, Greenberg, & Seltzer, 2012), employment status (Magliano et al., 2014), and relationship status (Magliano et al., 2014; Smith, Greenberg, & Seltzer, 2012).

**Individual variables.** Individual variables are those variables associated with personal demographics of the parent or the roles played by the parent. Increasing maternal age has been found to be associated with higher levels of positive affect and lower levels of negative affect in mothers of CSHCN (Smith, Greenberg, & Seltzer,
Family caregivers of CSHCN who are unemployed experience greater psychological burden than family caregivers who are employed (Magliano et al., 2014).

Family variables. Family variables are those variables associated with family structure or family life cycle stage. Marriage and/or cohabitation seems to moderate the effects of having a CSHCN. It has been found that family caregivers of CSHCN who did not live with a partner experienced greater practical burden than family caregivers who did live with a cohabiting partner (Magliano et al., 2014). Further, married mothers of adolescents and adults with ASD experience fewer depressive symptoms than their unmarried counterparts (Smith, Greenberg, & Seltzer, 2012). These findings inform the family structure variable of marriage/partnership status and the parent demographic variables of employment status/employment status of partner/spouse and age to be considered by the present study.

Family Resilience and CSHCN

Over the past two decades, extensive literature has conceptualized and examined coping, adaptation, and adjustment as components of resilience in families of CSHCN (Cohen, 1999; Rolland & Walsh, 2006.) Rather than report on the family resilience literature here, the present study begins with the premise that social support is an integral coping resource for family resilience (Hobfoll & Spielberger, 1992; Walsh, 2016) and focuses on the sources, mechanisms, and effects of the resource of social support for families of CSHCN.
Social Support for Families of CSHCN

The present study seeks to examine instrumental support as measured by hours of unpaid assistance provided in the past month by various informal and formal sources. Presently, I will summarize existing research on social support and families of CSHCN broadly before examining the literature specific to instrumental support and sources of instrumental support for families of CSHCN, as the literature on the specific domain of instrumental support is scant.

Effects of Social Support for Families of CSHCN

Social support has been linked with positive coping and adjustment for parents of children with a chronic illness (Horton & Wallander, 2001; Young & McCubbin, 2002). It is also negatively related to parental stress (Pedersen, Parsons, & Dewey, 2004; Senger, Ward, Barbosa-Leiker, & Bindler, 2016), distress, (Horton & Wallander, 2001), practical and psychological burden (Magliano et al., 2014), anxiety, complaints of physical health, depression (Lovell, Moss, & Wetherell, 2012), negative affect, and depressive symptoms (Smith, Greenberg, & Seltzer, 2012). Enhanced social support for parents has also been associated with improved illness management in adolescents (Carcone et al., 2011).

Both informal sources of support and formal sources of support seem to have positive effects on parental outcomes. Gouin, Da Estrela, Desmarais, and Barker (2016) examined the impact of informal support and formal support on both subjective and objective measures of health and found that both informal support (from a “special person,” family, and friends) and formal support service had largely independent effects.
on subjective and objective measures of health for parents of young and adult children with ASD. Informal support and formal support were both associated with subjective health measures, whereas formal support was also additionally associated with objective health measures (Gouin et al., 2016).

**Mechanisms of Social Support for Families of CSHCN**

Social support can act on individual and family outcomes via direct effects or indirect effects. Research on families of CSHCN has examined both direct effects and indirect effects of social support and has demonstrated that social support operates through both channels for this population.

Ekas and colleagues (2010) found that whether or not social support had a direct or indirect effect on outcomes depended on from whom the social support came (Ekas et al., 2010). Support from family was shown to have an indirect effect on both positive and negative maternal outcomes. However, both partner support and support from friends have a direct effect on positive maternal outcomes. As these various sources of informal support may operate via different mechanisms, the authors assert the importance of increasing both the amount and the quantity of multiple sources of informal and formal support available to mothers of children with ASD.

In a 2014 study, Fonseca, Nazaré, and Canavarro also found mixed results for the mechanism of social support depending on the source of social support, the recipient (mother or father), and the outcome measured. A mother’s satisfaction with social support from maternal family and friends was inversely related to both maternal and
Paternal satisfaction with social support from friends was significantly correlated with paternal burden, paternal parenting stress, and maternal parenting stress. Both fathers and mothers reported lower burden when the father was more satisfied with friend support. Finally, mothers and fathers both reported lower parenting stress when the mother was more satisfied with maternal family support.

Sources of Social Support for Families of CSHCN

In their landmark study, Kazak and Marvin (1984) compared the social networks of 56 families of children with spina bifida with 53 families of age matched healthy children. They found that the parents of children with spina bifida reported smaller, more dense networks than the comparison group. There was no significant difference in the size of the family network between the two groups. The difference in total network size was due to the smaller size in friendship network for the parents of children with spina bifida. Though this study did not examine specific functions of social support provided by network members, the findings lend credence to the expectation that we can expect the parents of CSHCN to report more instrumental support received from family than from friends, due to the limited size of friendship networks.

Patterson, Garwick, Bennett, and Blum (1997) studied both the social support and nonsupportive behaviors received by 182 families of young children with special health care needs. Both mothers and fathers reported that family members provided the most practical help, though the exact nature of the relationship with the family members providing support was not defined (i.e., parents vs. extended family). Additionally, both
mothers and fathers identified receiving practical help from family members as being more helpful than practical help from either community sources or formal service providers. Within the present study, it is expected that family will provide more unpaid assistance to the parents of the CSHCN than formal support sources. The present study will further seek to identify from which members of the family the most unpaid assistance comes and to identify how those sources might vary based on family and individual variables.

Sources of support identified in the recent literature on families of CSHCN include family members, friends, community, church, and the workplace (Brody & Simmons, 2007; Smith, Greenberg, & Seltzer, 2012). Pfeifer and colleagues (2013) identified family members as providing the most support, with spouses serving as the primary source of support, followed by the caregiver’s mother (Pfeifer et al., 2013). In the same study, mothers also mentioned their children as a source of social support. Guralnick and colleagues (2008) also identified intimate sources (i.e., spouses, partners), as providing the most support to mothers, followed by friends, extended family, and finally the community. Existing studies fail to quantify the amount of support provided from each source, which is a gap the present study attempts to fill.

**Informal sources of social support.** Kazak and Marvin (1984) note that “it is informal, rather than formal, social support networks which are more critical” to the families of children with special health care needs (p. 69). Informal support for parents of CSHCN from various sources, including partners, friends, and other family is
associated with lower levels of parenting stress, depressive symptoms, and negative affect as well as greater optimism, higher levels of life satisfaction, psychological well-being, and positive affect (Ekas et al., 2010). Informal sources of social support may vary throughout the life course and may include partners, parents, parents in-law, extended family, grown children, grandchildren, friends, neighbors, coworkers, and other community members.

Past studies have examined and demonstrated spousal support as a key source of informal support, however, those studies are limited in that they focus on married partners. For the present study, in an effort to examine varying family structures (i.e., single), spousal support will not be measured. Little research has examined support from specific family members (i.e., siblings, extended family), but there is a growing body of literature on the social support grandparents provide to the parents of CSHCN.

**Grandparents as an informal source of social support.** Grandparents may be a particularly salient source of instrumental support for parents of younger children with any type of special health care need, though most of the existing literature focuses on parents of children with disabilities. Though research has suggested that grandparents provide more emotional support than instrumental support (Seligman, Goodwin, & Paschal, 1997), when they do provide instrumental support, babysitting is the most frequent support activity engaged in (Sandler, 1995). Poor health and geographical distance may be two reasons grandparents provide more emotional support than instrumental support to the parents of CSHCN (Hornby & Ashworth, 1994).
When grandparents provide support to the parents of CSHCN, it has been reported that grandmothers provide more support than grandfathers (Seligman et al., 1997) and that maternal grandparents provide more support than paternal grandparents (Hornby & Ashworth, 1994; Seligman et al., 1997). The latter finding may be more reflective of the fact that the majority of study participants have been mothers who may perceive more support from their own parents. A strength of the current study is that not only does it examine support received from parents versus parents-in-law (among other sources), but it also provides more reports from fathers of CSHCN than is in the existing literature.

The relationship between grandparent support and parental adjustment may vary between mothers and fathers. Hastings, Thomas, and Delwiche (2002) found that grandparent support is significantly related to maternal stress but not paternal stress. On the contrary, Sandler (1995) found a positive correlation between paternal adjustment and grandparent support but not maternal adjustment. Yet another explanation is that it is emotional support from each parent’s own mother that is most important to adjustment (Trute, 2003). Though the current study will not examine the effects of support received from each source, it is noteworthy that the benefit of support may vary based on the source from which the support is received.

**Formal sources of social support.** Formal support receipt by families of CSHCN is studied much less than informal support. Families with limited informal supports may be more dependent on formal supports, as they are the same families that
are at greatest risk of social isolation and demoralization (Johnson & Blasco, 1997).

Though existing research largely fails to examine informal and formal support receipt concurrently, both formal support and informal support will be studied in the current study. This will provide insight as to whether families receiving less support from one source (i.e., informal) are receiving more support from the other source (i.e., formal) and which variables may be associated with the amount of support received.

The amount and type of formal support needed by a family depend on characteristics of the child’s health care needs as well as on structural, functional, and external family characteristics (Johnson & Blasco, 1997; Johnson & Kastner, 2005). The present study seeks to further identify which variables are associated with the receipt of formal sources of support.

Different types of formal support include financial, legal, health insurance benefits, respite waiver vouchers, early intervention, and special education programs. Instrumental, non-financial support can come in the form of child care, respite care, transportation, home modifications, training, crisis intervention, faith-based services, and assistance with the transition to adult group homes (Johnson & Kastner, 2005). Of these forms of instrumental support, respite care for families of children with developmental disabilities is perhaps the most studied in relation to CSHCN.

In an analysis of data from the 2001 Survey of Children with Special Health Care Needs, Nageswaran (2009) found that the need for respite care was associated with the age of the child with the health care need. Parents of younger children were more likely
to report a need for respite care. Additionally, those who either had public insurance or had gaps in health care coverage were more likely to express a need for respite care. Insurance type was also associated with the need for respite care being unmet. Surprisingly, children of mothers who had a high school degree or higher experienced a greater unmet need for respite care. Though need, met or unmet, may not be indicative of actual support provided and/or used, from these findings, I hypothesize for the present study that parents with young children and parents with lower income would report greater use of formal sources of support.

**Individual and Family Variables as Risk Factors for Low Social Support**

Individuals of lower income (less than $25,000) have been found to be almost six times as likely as those with higher income (greater than $75,000) to report no formal service use after their child with ASD graduates from high school. Additionally, African-Americans have been found to be more than three times as likely as Caucasian Americans to report no formal service use (Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011). In contrast, informal support use may have an opposite relationship with race and socioeconomic status. Nonwhite mothers of a CSHCN and mothers with less than a high school education have been shown to be more likely to report using friends and family as babysitters, whereas white mothers of CSHCN, mothers with a higher income, and more highly educated mothers have reported using more paid childcare (Suelzle & Keenan, 1981). Though these report on support use, these findings do not reveal whether or not formal services and unpaid assistance with childcare was available to the mothers who
reported using more paid childcare, it does lend insight as to the individual patterns of formal and informal support receipt expected to be observed in the present study.

In addition to finding that mothers of more than one child with ASD experience greater negative affect and decreased life satisfaction than mothers of only one child with ASD, Ekas and colleagues (2010) found that, when social support would seem to be even more salient to this group of individuals, mothers having more than one child with ASD also report receiving less support from all sources. While the present study does not identify whether or not a parent has more than one CSHCN, this may suggest that the number of children living in the home may be negatively related to the amount of social support received.

**Social Support over the Life Course for Parents of CSHCN**

Though it has been acknowledged that the impact of a child’s special health care need on the family varies with family life cycle stage (Rolland & Walsh, 2006), and that the use of social support varies over the life cycle of parents with CSHCN (Suelzle & Keenan, 1981), limited research has examined the dynamic nature of social support received by the families of CSHCN throughout the life cycle.

It is important to use a life course perspective when attempting to understand social support for parents of CSHCN. As the needs, roles, and circumstances of a parent change, the amount and type of social support they need will change as well. A parent’s roles change throughout the family life cycle. Each role played by the parent (both inside and outside the home) not only makes demands on the parent, but also provides
opportunities and access to resources. Social support needed and received thus changes when roles undergo change (Kahn & Antonucci, 1980).

Antonucci and Akiyama (1987) found that the oldest older adults (aged 75-95) received more support from fewer people. Additionally, a lower proportion of network members lived in close proximity, and there was less spouse and sibling membership but more friend membership in the most inner circle of the convoys of the old-old. Similarly, Boling (2011) reported that those over age 65 report fewer people to turn to for support in times of crisis and even fewer available to provide practical support. From these findings, I hypothesize that, regardless of the total hours of unpaid assistance reported, parents of CSHCN in the family life cycle stage of later life will report receiving unpaid assistance from fewer sources.

Social support is just as important to well-being later in life as it is early in life (Siedlecki, Salthouse, Shigehiro, & Jeswani, 2014). Formal service use has been shown to predict lower caregiving time demands and lower perceived burden in parents of children with intellectual disabilities (Haveman et al., 1997), and the impact of formal support does not seem to diminish with time. In fact, it has been found that the impact of formal support services on parental health is stronger for families of older children with ASD than younger children with ASD (Gouin et al., 2016). Though the importance of continued formal supports for parents of CSHCN throughout the life span has been noted (Gouin et al., 2016), the use of formal supports tends to decline as children get older (Haveman et al., 1997). There is a significantly steep decline in service use by
adolescents with ASD upon graduation from high school (Shattuck et al., 2011). This drop-off in formal support for parents may make the launching stage a particularly salient time for sources of informal support to be present.

The most informing examination of social support utilized by parents of CSHCN throughout the life cycle was conducted by Suelzle and Keenan in 1981. They studied 330 parents of children who required more than half of their time at school in a special education program. Though there were some demographic correlates of social support receipt, they found that the life cycle of the CSHCN was more strongly correlated to social support received than were demographic characteristics. Significantly, they found that the use of informal support declined over the life cycle. Specifically, decline in the use of family members or friends as babysitters was observed. The receipt of formal support also followed life cycle patterns as observed by unmet service needs for family support being reported (crisis lines, respite care, and counseling services). These unmet service needs followed a u-shaped pattern, with higher unmet needs reported by parents of preschoolers, followed by a drop in unmet needs for parents of elementary-aged children and adolescents, and the highest level of unmet needs reported among the parents of young adults. This pattern suggests that formal support may be particularly salient during periods of transition (i.e., entry into and exit from formal schooling).

Though they provided an overall portrait of declining use of informal support, Suelzle and Keenan failed to demonstrate the stage specific use of informal support, which could have helped enhance the understanding of the pattern of formal support use.
Other existing studies on formal support use neglect to report concurrent informal support use to identify any potential relationships between formal support use and informal support use. The present study attempts to fill this gap by examining both informal support received and formal support received by parents of CSHCN at different stages in the family life cycle.

**Summary and Hypotheses**

Existing literature examines and establishes the relationship between social support and resilience for families of CSHCN. However, a large gap remains, as existing literature largely fails to examine the specific functions and structure of formal and informal support received by the parents of CSHCN and the variables associated with support receipt throughout the life course. The current study seeks to fill in the gaps in existing research by focusing on the sources of instrumental support received by CSHCN and the life course variables associated with the sources of formal and informal support received.

The following objectives and hypotheses will guide this study:

Objective 1) To examine the amount of instrumental support parents of CSHCN receive from specific sources of informal (i.e., parents, in-laws, adult children, and other family/friends) and formal (i.e., volunteers, religious groups, private organization, and government agency) support.
Objective 2) To identify associations between the amount of instrumental support received by parents of CSHCN from informal sources and the amount of instrumental support received from formal sources.

Hypothesis 1) Parents will report more unpaid assistance from informal sources than formal sources at each family life cycle stage.

Objective 3) To identify how the total amount of instrumental support received by the parents of CSHCN and the amount of instrumental support received from specific informal and formal sources vary by parental demographic variables.

Hypothesis 2) Parent demographic variables will be related to the amount of unpaid assistance received from informal and formal sources.

2a) White parents will report more unpaid assistance from formal sources than non-white parents.

2b) Non-white parents will report more unpaid assistance from informal sources than white parents.

2c) Household income will be positively related to unpaid assistance from formal sources.

2d) Household income will be negatively related to unpaid assistance from informal sources.

Objective 4) To identify how the total amount of instrumental support received by the parents of CSHCN and the amount of instrumental support received from specific informal and formal sources vary by family structure variables.
Hypothesis 3) Family structure will be related to the amount of unpaid assistance received from informal and formal sources.

3a) The number of children in the household will be negatively related to unpaid assistance from informal sources and positively related to unpaid assistance from formal sources.

3b) Married/cohabiting parents will report more unpaid assistance from informal sources than single parents.

Objective 5) To identify how the total amount of instrumental support received by the parents of CSHCN and the amount of instrumental support received from specific informal and formal sources vary by family life cycle stage variables.

Hypothesis 4) Family life cycle stage will be related to the total amount of unpaid assistance received from all sources combined.

4a) Families with young children will report the most unpaid assistance from all sources combined.

4b) Families in later life will report the least amount of unpaid assistance from all sources combined.

I will also explore other family structure and demographic characteristics (i.e., multigenerational household, adult child living at home, religious participation) that prior research has largely ignored without testing specific hypotheses.
CHAPTER III

METHODS

Participants

The sample was obtained from the Midlife Development in the United States (MIDUS) survey. Data for Wave I of the MIDUS were collected from 1995-1996. The original field of participants included a nationally representative sample of 7,108 English-speaking 25- to 74-year olds. Data were re-collected for 4,963 participants again in 2004 for Wave II (MIDUS 2). In 2013, survey data were collected from 3,294 of the remaining original MIDUS participants for Wave III of the MIDUS survey (MIDUS 3). In an effort to replenish the original MIDUS I cohort, in 2011, data were collected from a new national sample of 3,577 English-speaking 25- to 74-year olds, constituting the MIDUS Refresher. The current study includes data from 489 parents of a child with special health care needs from Wave III (Ryff et al., 2013-2014) and the Refresher data (Ryff et al., 2011-2014). Data for this study come from participants’ responses to a phone interview and a self-administered questionnaire (SAQ).

Sample Characteristics

The study sample included 489 individuals who had a child with special health care needs. The study sample reflected the larger MIDUS sample; 88% of respondents were white, and ranged in age from 29 to 92 years, with a mean age of 63. Thirty-six percent were male and 64% female. Over 55% had a bachelor’s degree or higher, and the
average income was over $79,000. (These and other parent demographic variables can be seen in Table 1).

Table 1

Sample Characteristics

<table>
<thead>
<tr>
<th>Sample Characteristics</th>
<th>N</th>
<th>% Total</th>
<th>Mean (S.D.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>489</td>
<td>63.25 (12.24)</td>
<td></td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td>$79,669 (70,037)</td>
<td></td>
</tr>
<tr>
<td>Number of Children</td>
<td></td>
<td>3.01 (1.81)</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>177</td>
<td>36.2%</td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>312</td>
<td>63.8%</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>430</td>
<td>87.9%</td>
<td></td>
</tr>
<tr>
<td>Non-white</td>
<td>57</td>
<td>11.7%</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Less than high school</td>
<td>31</td>
<td>6.3%</td>
<td></td>
</tr>
<tr>
<td>HS or some college</td>
<td>187</td>
<td>38.2%</td>
<td></td>
</tr>
<tr>
<td>Bachelor’s or higher</td>
<td>270</td>
<td>55.2%</td>
<td></td>
</tr>
<tr>
<td>Employment Status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working for pay</td>
<td>218</td>
<td>44.6%</td>
<td></td>
</tr>
<tr>
<td>Not working for pay</td>
<td>179</td>
<td>36.6%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>9</td>
<td>1.8%</td>
<td></td>
</tr>
<tr>
<td>Spouse/Partner Employment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working for pay</td>
<td>139</td>
<td>48.6%</td>
<td></td>
</tr>
<tr>
<td>Not working for pay</td>
<td>138</td>
<td>48.3%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>9</td>
<td>3.1%</td>
<td></td>
</tr>
<tr>
<td>Married/Cohabiting</td>
<td>158</td>
<td>32.3%</td>
<td></td>
</tr>
<tr>
<td>Adult Child Living at Home</td>
<td>133</td>
<td>27.2%</td>
<td></td>
</tr>
<tr>
<td>Multigenerational Household</td>
<td>10</td>
<td>2.0%</td>
<td></td>
</tr>
<tr>
<td>Religious Community</td>
<td>283</td>
<td>58.4%</td>
<td></td>
</tr>
</tbody>
</table>

Measures

For inclusion in the study, respondents had to have a child with special health care needs. Additionally, variables of interest included both formal and informal sources of
parental instrumental support as well as life course variables that included parent
demographic characteristics, family structure, and family life cycle stage.

**Child with Special Health Care Needs**

Participants were asked to identify whether they had a child with a “chronic
disease or disability” (yes=1, no=0) within the last 12 months. Parents who responded
“yes” were classified as having a child with a special healthcare need. Parents who
responded “no” were classified as not having a child with a special health care need.

**Parental Instrumental Support**

For the purpose of the present study, instrumental support was measured by the
reported hours of unpaid assistance received in the previous month from various informal
and formal sources.

**Informal sources of instrumental support.** Parental informal instrumental
support was measured with four items related to instrumental support receipt: Received
unpaid assistance from parents, received unpaid assistance from in-laws, received
unpaid assistance from grown children or grandchildren, and received unpaid assistance
from other family/friends. Each measure was assessed by asking one question detailing
the number of hours per month the respondent received unpaid assistance from each
support source. Though the specific dimensions of instrumental support were not
measured, respondents were given the examples of help around the house, transportation,
or childcare as an example of what instrumental support entails. A composite variable of
total informal support was constructed by summing the total hours of unpaid assistance received from all informal sources.

**Formal sources of instrumental support.** Parental formal instrumental support was measured with four items related to instrumental support receipt: *Received unpaid assistance from community volunteers, received unpaid assistance from religious groups, received unpaid assistance from any other non-governmental organization, cause, or charity, and received unpaid assistance from any government group or agency.* Each measure was assessed by asking one question detailing the number of hours per month the respondent received unpaid assistance from each support source. Though the specific dimensions of instrumental support were not measured, respondents were given the examples of help around the house, transportation, or childcare as an example of what instrumental support entails. A composite variable of total formal support was constructed by summing the total hours of unpaid assistance received from all formal sources.

**Life Course Variables**

Life course variables to be measured were classified into three categories; parent demographic characteristics, family structure, and family life cycle stage.

**Parent demographic characteristics.** Seven parent demographic characteristics were considered as detailed below.

**Age.** Respondent age was calculated by subtracting date of birth from the date of the interview. Parent age was treated as a continuous variable.
Gender. Gender was measured as a dichotomous variable (1=male, 0=female).

Race. Respondents were asked via interview to identify their main racial origins. Response categories include White, Black and/or African American, Native American or Alaska Native Aleutian Islander/Eskimo, Asian, Native Hawaiian or Pacific Islander, Other, Don’t Know/Not Sure, and Refused. For the present study, responses were dichotomized (1=White/Caucasian, 0=racial/ethnic minorities).

Religious participation. Respondents were asked via SAQ to indicate whether or not they have a religious community or congregation (1=yes, 0=no).

Income level. Respondents were asked via SAQ to indicate total household income. Income was treated as a continuous variable.

Employment status/Employment status of partner/spouse. Respondents were asked via interview to identify their current employment situation as well as that of their partner/spouse. Responses were classified into 13 categories, including working now, self-employed, looking for work; unemployed, temporarily laid off, retired, homemaker, full-time student, part-time student, maternity or sick leave, permanently disabled, refused, don’t know/not sure, and other. For the present study, responses were re-coded to (0=working for pay, 1=not working for pay, 2=other).

Family structure. Family structure was coded into the four categories detailed below.

Marriage/partnership status. Respondents were asked, “Are you married, separated, divorced, widowed, or never married?” (1=married, 2=separated, 3=divorced, 4=widowed, 5=never married).
Respondents were also asked, “Are you currently living with someone in a steady, marriage-like relationship?” (1=yes, 0=no). For the present study, responses were dichotomized (1=married/cohabiting, 0=not married or cohabiting).

**Family size.** Respondents were asked to indicate the number of living children they have, (including biological, adopted, step, and foster). Family size is a continuous variable.

**Multigenerational household.** Respondents were asked to identify how each household member is related to them. If the respondent indicated any household member to be the respondent’s parent, step-parent, or grandparent, the respondent was identified as being a member of a multigenerational household (1=yes, 0=no).

**Families with adult children living at home.** Respondents were asked if they have any adult children (age 18+) living at home (1=yes, 0=no).

**Family life cycle stage.** The age of the youngest child served as a proxy for family life cycle stage. Participants were asked to indicate the age of each child and whether or not that child resided in the household. To create this variable, I coded the family life cycle into four categories described below:

**Families with young children.** Participants who identified their youngest child as being age 10 or younger were classified as being at the stage of families with young children.
Families with adolescents. Participants who identified their youngest child as being between the ages of 11 and 17 were classified as being at the stage of families with adolescents.

Families in midlife. Participants who identified their youngest child as being between the ages of 18 and 40, were classified as being at the stage of families in midlife.

Families in later life. Participants who identified their youngest child as being age 41 or older, were classified as being at the stage of families in later life.

Analysis Strategy

First, I examined descriptive statistics to identify the specific sources of informal and formal support received by parents of children with special health care needs (Objective 1). Prior to conducting regression analyses, I also examined correlations between parent demographic variables and the amount of support received from various sources to determine which covariates needed to be considered as potential control variables.

Next, I used Pearson correlations to identify any relationship between the total amount of unpaid assistance received overall by parents of CSHCN from informal sources of support and the total amount of unpaid assistance received from formal sources of support (Objective 2). I also used Pearson correlations to examine the associations between the amount of unpaid assistance received from specific sources of informal and formal support.
Next, I conducted a series of logistic regressions to analyze the associations between the receipt of unpaid assistance from formal sources and informal sources and parent demographic variables (Objective 3), family structure variables (Objective 4), and family life cycle stage variables (Objective 5). Formal and informal support were recoded into dichotomous variables due to skewness (0 hours=0, greater than 0 hours=1). Each model was run twice; first to predict the receipt of unpaid assistance from formal sources and then to predict the receipt of unpaid assistance from informal sources. Based on previous findings (Suelzle & Keenan, 1981; Nageswaran, 2009), race and income were controlled for in all models. Results from the logistic regression models can be found in Table 4.

Finally, I used analysis of variance (ANOVA) to examine mean differences by family life cycle stage in the total amount of unpaid assistance received from informal and formal sources (Objective 5b). I used a one-way ANOVA, where family life cycle was the between person effect (i.e., families with young children, families with adolescents, families in midlife, and families in later life).

I also used ANOVA to examine mean differences by family life cycle stage in the amount of unpaid assistance received from specific informal sources of support. I used a one-way ANOVA, where family life cycle was the between person effect (i.e., families with young children, families with adolescents, families in midlife, and families in later life).
CHAPTER IV

RESULTS

Descriptive Results (Objective 1)

I first examined descriptive statistics for family life cycle stages, support received from informal sources, and support received from formal sources, including the hours of unpaid assistance received from each source of informal and formal support.

Family Life Cycle Stage

Forty-eight and a half percent of participants belonged to a family in mid-life (youngest child age 18 through 40; \( n=237 \)), 30.3% to a family in later life (youngest child age 41 or older; \( n=148 \)), 11.3% to a family with young children (youngest child age 10 or younger; \( n=55 \)), and 9.5% to a family with adolescents (youngest child age 11 through 18; \( n=46 \)). Three cases were missing results for the number of hours of unpaid assistance received.

Support Received from Informal Sources

Overall, on average, parents reported receiving just under nine hours (8.86) of unpaid assistance from informal sources. Comparing informal sources of support, parents reported receiving the most unpaid assistance from children (5.04 hours/month), followed by other family/friends (2.82 hours/month), their own parents (0.94 hours/month), and finally their in-laws (0.32 hours/month). The mean amount of unpaid assistance received from each informal source also varied by family life cycle stage (See Table 2).
Support Received from Formal Sources

Overall, on average, parents reported receiving less than two hours (1.69) of unpaid assistance received from formal sources. Comparing formal sources of support, parents reported receiving the most unpaid assistance from religious groups (0.88 hours/month), government groups (0.55 hours/month), other organizations (0.16 hours/month), and finally from community volunteers (0.12 hours/month). The mean amount of unpaid assistance received from each formal source varied by family life cycle stage (See Table 2).

Table 2
**Formal and Informal Support Receipt by Family Life Cycle Stage**

<table>
<thead>
<tr>
<th>Life Cycle Stage</th>
<th>Young Children (n=55)</th>
<th>Adolescents (n=46)</th>
<th>Midlife (n=237)</th>
<th>Later Life (n=148)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Religious Groups</td>
<td>1.08 (3.55)</td>
<td>2.31 (11.45)</td>
<td>.88 (6.87)</td>
<td>.36 (2.06)</td>
</tr>
<tr>
<td>Gov’t Groups</td>
<td>.59 (4.20)</td>
<td>.00 (0.00)</td>
<td>.98 (10.24)</td>
<td>.02 (.192)</td>
</tr>
<tr>
<td>Comm. Volunteers</td>
<td>.35 (1.78)</td>
<td>.05 (.31)</td>
<td>.02 (.20)</td>
<td>.22 (1.63)</td>
</tr>
<tr>
<td>Other Organizations</td>
<td>.24 (1.42)</td>
<td>.02 (.15)</td>
<td>.09 (.88)</td>
<td>.27 (2.18)</td>
</tr>
<tr>
<td><strong>Total from Formal</strong></td>
<td><strong>2.25 (7.47)</strong></td>
<td><strong>2.33 (11.45)</strong></td>
<td><strong>1.94 (12.25)</strong></td>
<td><strong>.86 (3.86)</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Informal Sources Mean Hours of Unpaid Assistance (S.D.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children</td>
</tr>
<tr>
<td>Other Family/Friends</td>
</tr>
<tr>
<td>Parents</td>
</tr>
<tr>
<td>In-Laws</td>
</tr>
<tr>
<td><strong>Total from Informal</strong></td>
</tr>
</tbody>
</table>

Comparing Support Received from Formal and Informal Sources (Objective 2)

Next, I examined associations between instrumental support received from informal and formal sources and associations between family life cycle stage and
instrumental support receipt, using Pearson correlations and analysis of variance (ANOVA).

**Relationship Between Support from Informal and Formal Sources**

I used Pearson correlations to explore the relationship between the amount of unpaid assistance received from informal sources and the amount of unpaid assistance received from formal sources. A significant positive association was found ($r = .109, p = .019$) between the amount of unpaid assistance received from formal sources and informal sources. As parents receive more support from formal sources, they also receive more support from informal sources.

**Relationship Between Support from Specific Sources**

I also used Pearson correlations to identify any relationships between the amount of unpaid assistance received from specific sources of formal or informal support. Significant findings indicated only positive relationships between the amount of unpaid assistance received from various sources and no negative relationships, indicating that receiving more support from one source is associated with the receipt of less support from other sources. On the contrary, greater support from one source is often associated with greater support from other sources as well. Results can be found in Table 3.
Table 3
Correlations between the Amount of Unpaid Assistance Received from Various Sources

<table>
<thead>
<tr>
<th>Source of Support</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Formal Sources</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Relig Groups</td>
<td>-.009</td>
<td>.126**</td>
<td>.077</td>
<td>.095*</td>
<td>.176***</td>
<td>.063</td>
<td>-.006</td>
<td></td>
</tr>
<tr>
<td>2. Govt Groups</td>
<td>-.006</td>
<td>-.006</td>
<td>-.018</td>
<td>-.016</td>
<td>-.008</td>
<td>-.006</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. CommVolun</td>
<td>.327***</td>
<td>.074</td>
<td>.064</td>
<td>.138**</td>
<td>.102*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Other Orgs.</td>
<td>.069</td>
<td>.028</td>
<td></td>
<td>.112*</td>
<td>.023</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Informal Sources</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Children</td>
<td>.237***</td>
<td>.210***</td>
<td>.046</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Fam/Friends</td>
<td></td>
<td>.072</td>
<td>.103*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Parents</td>
<td></td>
<td></td>
<td>-.005</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. In-Laws</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* * * p < .05, ** p < .01, *** p < .001

Logistic Regression (Objectives 3 through 5)

I conducted a series of logistic regressions using three models. Model one examined parent demographic characteristics, model two examined family structure variables, and model three examined family life cycle stage variables. Results from the logistic regression models can be found in Table 4.

Model 1: Parent Demographic Characteristics (Objective 3)

Model 1 addresses Objective 3, where it was expected that the amount of instrumental support received would vary by parent demographic variables. Predictors entered into Model 1 included gender, age, employment status, employment status of spouse/partner, and religious participation.

**Formal support findings.** Though I had expected that white race and income would be positively associated with the receipt of formal support, neither race nor income was associated with the receipt of unpaid assistance received from formal sources (Table
4). However, religious participation and gender were significantly associated. Parents who reported being a part of a religious community or congregation were more than 28 times more likely to report receiving unpaid assistance from formal sources. Women were almost five times more likely to receive unpaid assistance from formal sources than were men. Neither the employment status of the respondent nor the spouse/partner significantly predicted the receipt of formal support.

**Informal support findings.** The association between religious participation and informal support approached significance (Table 4). Parents who reported being a part of a religious community or congregation were over one and a half times more likely to report receiving unpaid assistance from informal sources. Though it had been expected that non-white race would be positively related and income would be negatively related to the receipt of support from informal sources, there no significant associations were found. There was also no significant association found between any other parent demographic variables and unpaid assistance received from informal sources.

**Model 2: Family Structure Variables (Objective 4)**

Model 2 addresses Objective 4, where it was expected that the amount of instrumental support received would vary by family structure variables. Predictors entered into Model 2 included marriage/cohabitation status, number of living children, an adult child living at home, and living in a multigenerational household.

**Formal and informal support findings.** Hypothesis 3 was not supported. There were no significant associations between the number of children or parent
marriage/cohabitation status and the receipt of unpaid assistance from either formal or informal sources. There were also no significant associations found between any of the other variables of family structure and the receipt of formal or informal support.

**Model 3: Family Life Cycle Stage Variables (Objective 5)**

Family life cycle stage was dummy coded, where families with young children was the reference group. Again, logistic regression analysis was used to examine differences in support receipt based on family life cycle stage. Predictors entered into Model 3 included belonging to a family with young children, family with adolescents, family in midlife, and family in later life.

**Formal support findings.** Hypothesis 4 was partially supported. There was a trend for parents belonging to families in later life to be less likely to receive unpaid assistance from formal sources than families with young children (the reference group); however, this association did not reach statistical significance \( p = .096 \). Consistent with the Pearson correlation reported above, there was no significant association found between belonging to a family with young children and the receipt of unpaid assistance from formal sources. However, though not statistically significant, examining mean amounts of total hours of unpaid assistance received, descriptive results indicate that parents belonging to a family with young children reported receiving more unpaid assistance from formal sources (2.25 hours) than parents from families at any other life cycle stage.
Informal support findings. There was a significant association between informal support receipt and midlife and later life family life cycle stages. Parents belonging to families in later life were about 50% less likely than those belonging to families with young children to report receiving unpaid assistance from informal sources. Additionally, parents belonging to families in midlife were about 40% less likely than those belonging to families with young children to report receiving unpaid assistance from informal sources.

Family Life Cycle Differences in Total Support (Objective 5b)

First I used a one-way repeated measures ANOVA to examine whether total support received from informal sources was significantly different from total support received from formal sources. In this model, support source is a within-person effect. Results revealed a main effect of support source \( F(1,461) = 25.60, p < .001 \). Parents received significantly more unpaid assistance from informal sources \( M = 8.87, SD = 29.95 \) than from formal sources \( M = 1.69, SD = 9.80 \). Next, I examined mean differences in support by family life cycle stage separately for total hours of unpaid assistance from formal and informal sources.
Table 4  
**Logistic Regression Results**

<table>
<thead>
<tr>
<th></th>
<th>Formal Support</th>
<th></th>
<th>p</th>
<th>Informal Support</th>
<th></th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Model 1 Parent Demographic Characteristics (n=237)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td>.913 (.633)</td>
<td>2.493</td>
<td>.149</td>
<td>-.729 (.509)</td>
<td>.482</td>
<td>.152</td>
</tr>
<tr>
<td>Income</td>
<td>.000 (.000)</td>
<td>1.000</td>
<td>.583</td>
<td>.000 (.000)</td>
<td>1.000</td>
<td>.657</td>
</tr>
<tr>
<td>Age</td>
<td>-.009 (.023)</td>
<td>.991</td>
<td>.700</td>
<td>-.001 (.014)</td>
<td>.999</td>
<td>.939</td>
</tr>
<tr>
<td>Gender</td>
<td>1.549 (.515)</td>
<td>4.707</td>
<td>**.003</td>
<td>-.003 (.280)</td>
<td>.997</td>
<td>.993</td>
</tr>
<tr>
<td>Religious Community</td>
<td>3.335 (1.040)</td>
<td>28.071</td>
<td>**.001</td>
<td>.516 (.276)</td>
<td>1.675</td>
<td>.061</td>
</tr>
<tr>
<td>Employment Status</td>
<td>.242 (.461)</td>
<td>1.274</td>
<td>.600</td>
<td>-.330 (.268)</td>
<td>.719</td>
<td>.218</td>
</tr>
<tr>
<td>Partner Employment Status</td>
<td>.008 (.446)</td>
<td>1.008</td>
<td>.985</td>
<td>-.554 (.833)</td>
<td>1.104</td>
<td>.506</td>
</tr>
<tr>
<td><strong>Model 2 Family Structure (n=441)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marriage/Cohabitation</td>
<td>-.296 (.325)</td>
<td>.744</td>
<td>.362</td>
<td>-.358 (.222)</td>
<td>.699</td>
<td>.107</td>
</tr>
<tr>
<td># of Children</td>
<td>.070 (.070)</td>
<td>1.073</td>
<td>.314</td>
<td>.085 (.059)</td>
<td>1.089</td>
<td>.150</td>
</tr>
<tr>
<td>Adult Child at Home</td>
<td>.185 (.320)</td>
<td>1.203</td>
<td>.563</td>
<td>.320 (.219)</td>
<td>1.377</td>
<td>.144</td>
</tr>
<tr>
<td>Multigen Household</td>
<td>1.071 (.759)</td>
<td>2.918</td>
<td>.158</td>
<td>.775 (.733)</td>
<td>2.171</td>
<td>.290</td>
</tr>
<tr>
<td><strong>Model 3 Family Life Cycle Stage (n=440)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adolescents</td>
<td>-.063 (.551)</td>
<td>.939</td>
<td>.909</td>
<td>-.620 (.419)</td>
<td>.538</td>
<td>.139</td>
</tr>
<tr>
<td>Midlife</td>
<td>-.606 (.415)</td>
<td>.545</td>
<td>.144</td>
<td>-.891 (.317)</td>
<td>.410</td>
<td>**.005</td>
</tr>
<tr>
<td>Later Life</td>
<td>-.774 (.465)</td>
<td>.461</td>
<td>.096</td>
<td>-.714 (.338)</td>
<td>.490</td>
<td>*.035</td>
</tr>
<tr>
<td>Constant</td>
<td>-1.397 (.408)</td>
<td>.247</td>
<td>.001</td>
<td>.461 (.313)</td>
<td>1.586</td>
<td>.141</td>
</tr>
</tbody>
</table>

Notes. * p <.05., ** p <.01
**Formal Support Findings**

There were no significant differences by family life cycle stage in the receipt of support from formal sources.

**Informal Support Findings**

Results revealed a significant main effect of family life cycle stage for the amount of support received from informal sources ($F(3, 476) = 15.06, p < .001$). The Bonferroni post hoc test indicated that the families with young children reported receiving significantly more unpaid assistance compared to families at all other life stages ($p < .05$).

**Family Life Cycle Stage and Support from Specific Informal Sources**

Next, I used ANOVA to identify mean differences by family life cycle stage in the amount of unpaid assistance received from specific informal sources of support. Results revealed a significant main effect of family life cycle stage for receipt of informal support from children ($F(3, 454 = 6.55, p < .001$); from other family/friends ($F(3, 458) = 6.02, p < .001$), and from parents ($F(3, 456) = 11.41, p < .001$). The Tukey HSD post hoc test indicated that the families with young children reported receiving significantly more unpaid assistance compared to families at all other life stages ($p < .05$). The Bonferroni post hoc tests indicated that parents with young children received significantly more support from their children compared to parents at all other family life cycle stages ($ps < .01$). Post hoc tests indicated that parents with young children and parents with adolescent children received significantly more support from their children compared to parents at midlife or later life ($ps < .01$). Finally, post hoc tests indicated that
parents with young children received significantly more support from their parents compared to parents at all other life cycle stages ($ps < .01$).
CHAPTER V

DISCUSSION

The purpose of this study was to gain a deeper understanding of the instrumental support received by parents of children with special health care needs (CSHCN) throughout the life course. The study provided a description of the sources of unpaid assistance for the parents of CSHCN and yielded significant findings regarding variations in support receipt associated with life course variables. Parents receive significantly more instrumental support from informal sources than from formal sources at each stage of the family life cycle. Additionally, a significant positive relationship exists between the amount of support received from formal sources and the amount of support received from informal sources. The receipt of support from specific sources also demonstrates a relationship with the receipt of support from other specific sources. Finally, life course variables including religious participation and gender were associated with the receipt of support from formal sources, whereas family life cycle stage was associated with the receipt of support from informal sources. Parents from families with young children reported receiving significantly more unpaid assistance from informal sources than parents from families at all other life cycle stages. These findings point to potential areas for future research.
Sources of Support

This study revealed that, across the life course, parents of CSHCN receive, on average, more unpaid assistance from their children than from any other source. Caution must be used when interpreting this and other descriptive findings, as the statistical significance of this difference was not analyzed in the present study. It is important that future studies test for such significance. This study’s descriptive findings also suggest that for parents belonging to families in midlife, at a time when there may be fewer members in the support network to provide support (Antonucci & Akiyama, 1987), and the amount of unpaid assistance received from all sources may be in decline (Boling, 2011), the amount of unpaid assistance from children may start to increase. This increasing dependence on one’s own children for assistance may have costs for both parent and child including stress, feelings of burden, and emotional exhaustion. However, it may also provide rewards, giving the caregiver a sense of competence, relational closeness, and pride in having been able to “pay back” one’s parent. Research has begun to look at the balance of costs and rewards in caregiving contexts (Raschick & Ingersoll-Dayton, 2004).

Apart from family and friends, parents receive more unpaid assistance from religious organizations than from any other formal source of support. Since social support does not decline in importance over the life course (Siedlecki, Salthouse, Shigehiro, & Jeswani, 2014), programs should be developed to help parents maintain supportive ties throughout the life course. Religious communities may provide a key avenue for building and maintaining such ties. Parents of CSHCN have reported that not
only their religious beliefs but also the support they receive from religious communities and organizations have been valuable for coping (Canary, 2008).

**Formal and Informal Support**

Consistent with previous research (Patterson et al., 1997), parents received significantly more support from informal sources than from formal sources at each stage of the family life cycle. This finding is important, as it is support from informal sources which has been presumed to be most important for families of CSHCN (Kazak & Marvin, 1984). It has also been presumed that families with limited support from informal sources could be in greater need of support from formal sources, as they are the same families that have a greater risk of social isolation and demoralization (Johnson & Blasco, 1997). Despite this need, findings from the current study demonstrate a positive relationship between the receipt of support from informal and formal sources, indicating that the parents who most need support from formal sources (those receiving little support from informal sources) do not necessarily receive this support. This suggests that parents may either be support rich or support poor, as the same parents who receive more support from informal sources also receive more support from formal sources. Further research should attempt to identify a threshold of instrumental support from formal and informal sources both combined and independently that may be most beneficial for the parents of CSHCN.

**Parent Demographic Characteristics and Support Receipt**

An additional goal of the study was to examine how parent demographic characteristics are associated with instrumental support receipt. Parents who reported
being a part of a religious community or congregation were significantly more likely to report receiving unpaid assistance from formal sources. This could be due to the fact that unpaid assistance from religious organizations was a part of the construct of formal support. Regardless, it does point to the potential benefits available to members of a religious community. The association between religious participation and informal support approached significance. Individuals who belong to a religious community may not only have support available from the church or congregation, but may also have additional support available from friends and family as well. This is consistent with previous findings, which have suggested that the level of involvement in a religious community is predictive of the provision of support (McClure, 2013). It is logical then to assume that those who participate in a religious community not only provide more support but also benefit from receiving the support provided by other members of the religious community. Future research should examine any potential differences in support receipt based on the type of religious or denominational community to which the individual belongs (i.e., Protestant, Catholic, Islamic, Jewish).

Gender was also found to be significantly associated with the receipt of formal support. Women were almost five times more likely to receive unpaid assistance from formal sources than were men. This is consistent with previous research examining mother-father dyads, which demonstrated that mothers of children with disabilities are more likely to express a need for various forms of support than are fathers (Bailey & Simeonsson, 1988). Gender differences in family roles may certainly contribute to these findings. With mothers typically serving as the primary caregivers and coordinators of
medical care for their children, it is likely that they are the parents more in need of instrumental support with tasks like childcare.

Other studies have provided mixed findings on gender. A 2006 meta-analysis of caregiver research revealed no gender difference in formal support receipt (Pinquart & Sörensen, 2006). However, among aging adults with disability, women have been found to be much more likely to live alone, to be much less likely to live with a spouse, and to receive fewer hours of support from informal sources (Katz, Kabeto, & Langa, 2000). These factors may similarly contribute to a greater need for formal support for mothers of CSHCN and subsequent receipt of support from formal sources as found in the present study. Previous research has largely examined paid formal support or has not distinguished between paid or unpaid formal support which may explain different findings. Future research on parents of CSHCN should control for the effects of aging and should seek to distinguish between paid and unpaid support from formal sources to confirm the gender differences found in the present study.

**Family Structure and Support Receipt**

In contrast, results revealed no significant associations between family structure variables and the receipt of support from either formal or informal sources. This may indicate that parents receive support from formal and informal sources regardless of family structure, however it is support from specific sources which varies with family structure, something the present study did not examine.

For example, previous research has suggested mixed findings on family structure’s influence on the support received by parents from adult children. Children of
divorced frail parents have been shown to be less likely to give care to their fathers, but to be just as likely as adult children of married frail parents to provide care to their mothers (Lin, 2008). The number and gender of adult children has also been shown to influence the type and amount of support received by parents from their children (Spitze & Logan, 1990), having at least one daughter being a key variable associated with parents receiving instrumental support from adult children. Additionally, support from parents provided to adult children has been shown to be greater for children who are considered by their parents to have more problems (Fingerman, Miller, Birditt, & Zaritt, 2009). Finally, previous findings suggest that mothers of children with ASD who do not live with a partner are more likely to report less support from formal sources and from family and that mothers of a son with ASD are more likely to report less support from some sources of informal support than are the mothers of girls with ASD (Bromley, Hare, Davison, & Emerson, 2004).

Future research should include additional family structure variables such as gender of all children as well as the child with special health care needs. Additionally, future research should use a continuous measure of support, as it may be that family structure is more strongly associated with the amount of support received, rather than whether it is or is not received (a limitation of the use of a dichotomous variable in the present study).

**Family Life Cycle Stage and Support Receipt**

Results of ANOVA revealed that parents of families with young children reported receiving significantly more support from informal sources than parents from families at
any other life cycle stage. Consistent with prior research on parents of CSHCN (Suelzle & Keenan, 1981) and literature on social support in general (Boling, 2011), regression analyses confirmed that parents belonging to families in midlife and later life receive significantly less support from informal sources than parents belonging to families with young children. Midlife and later life parents of CSHCN, as part of the “sandwich generation”, may now be playing a caregiving role for their own aging parents and may be providing assistance in caring for their own grandchildren. Even if they are not filling such caring roles, the support available to them from their parents may be greatly diminished due to death or disability, and that available from their children by relocation and/or the responsibilities of providing for their own growing families.

There was also a trend for parents belonging to families in later life to be less likely to receive unpaid assistance from formal sources as well, which reflects previous findings (Suelzle & Keenan, 1981). This could be reflective of parents of young children receiving more unpaid assistance in the form of child care provided by family and friends (Suelzle & Keenan, 1981). For parents of typical children, the need for such assistance diminishes over the family life cycle, as children age and become more independent. For the parents of children with profound intellectual or physical disabilities though, this need for child care assistance from informal or formal sources may not diminish over the life course. For these parents, less support may be available, though such support is just as important (Gouin et al., 2016).
Limitations and Future Directions

Despite the study’s contributions, the study is not without limitations. First, the present study only examines instrumental support received and does not examine the need for or availability of instrumental support from various sources. Respondents who did not receive support from a source may have had support available from that source but simply may not have needed or wanted that support for various reasons. Thus, caution should be used when assuming the lack of received support from a particular source implies the lack of available support from that source.

Secondly, the sample was predominantly white and middle class, limiting the ability to generalize the findings. With a more diverse sample, there may be more observable differences in support receipt based on family structure. Among racial minorities who rely more on the group support available from kin networks, we might expect to see significant relationships between informal support receipt and family structure variables like multigenerational household status, family size, and marital status.

Next, defining family life cycle stage only by the age of the youngest child may miss much of the dynamic family variables that define the life cycle stage. (For example, blended families who have both grown children who have launched and a young child still at home will have significantly different experiences from families with just one young child.) Additionally, by not considering the type of diagnosis in this study, important differences in the variance of the type and amount of support needed are ignored. For example, the parents of a child who is permanently home bound and
ventilator dependent will likely vary significantly throughout the life course from the parents of a child with asthma who will easily take over their own care as they grow into adulthood.

Further, by dichotomizing the receipt of support from formal and informal sources for regression analysis, rich findings on the relationship between support receipt and life course variables (i.e., family structure) may have been missed. Finally, the cross-sectional nature of the study allowed me to examine how instrumental support varies between family life cycle stages. It did not allow me to examine changes in instrumental support through the life course. As the MIDUS does provide longitudinal data, future research should seek to explore how instrumental support for parents of CSHCN changes throughout the life course.

This is the first study to demonstrate a relationship between the receipt of support from formal and informal sources for the parents of CSHCN. Future studies should seek to repeat this finding with not only instrumental support but other domains of support (i.e., financial, informational, emotional) as well as with global support measures. Future research should also explore the avenues through which religious communities provide instrumental support, disentangling whether such support is provided most through formal systems of support (i.e., organized group respite care opportunities and transportation services) or through informal support from congregation members (i.e., meal provision and help with in-home childcare). Future research should seek to identify which types of instrumental support provided by religious organizations might be most beneficial, as well as to develop ways that non-religious organizations might be able to
provide the same type of support to families who are not likely to either seek or be receptive to support from a religious organization.

Though it was found that women received more support from formal sources than men, the present study did not examine the reasons why. Future research should examine if the mothers of CSHCN are more receptive to help and more likely to seek assistance from formal sources than men or if other factors affect this discrepancy in support receipt. The MIDUS only includes data from one family member, so without dyadic data, it is difficult to know how mothers and fathers within the same family differ from one another in support receipt. It is likely that mothers and fathers from the same family would differ in their reports of support receipt, due to the gendered nature of caregiving.

Future research should also seek to identify the extent to which the need for unpaid assistance (for example with child care) is met or unmet by different formal and informal sources throughout the family life cycle. Similarly, additional research that considers the specific stages of the family life cycle and the age of the CSHCN could be useful to provide more insight about what support is needed for the parents of CSHCN at different levels of individual and family development. Other variables affecting the availability of instrumental support should also be considered, such as the distance lived from family and the type of community in which the family resides (i.e., rural or urban).

**Conclusion**

This study contributes a greater understanding of the variance in instrumental support receipt for parents of children with special health care needs throughout the life course. Though it is a domain of support that may be especially salient for parents of
CSHCN, instrumental support in the form of unpaid assistance has been largely neglected in prior studies. The findings of this study suggest that the parents of CSHCN receive more support from informal sources at each stage of the family life cycle than from formal sources. Additionally, the receipt of instrumental support from formal sources is associated with the receipt of support from informal sources. Finally, gender, religious community, and family life cycle stage may be particularly predictive of the sources of instrumental support utilized by parents of CSHCN. These findings can help make medical, educational, and social service providers aware of individuals who may need assistance securing instrumental support from both informal and formal sources which may not be readily available or even known to them.
REFERENCES


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