

Intellectual and Developmental Disabilities

Compound Caregiving: Toward a Research Agenda

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Abstract:	Aging family caregivers of adults with intellectual and developmental disabilities (IDD) have unique circumstances setting them apart from the general caregiving population. Such differences include the extensive duration of the caregiving, and health concerns which manifest in the caregiver and individuals with IDD over time. Because of increasing longevity, family caregivers are likely to become compound caregivers (i.e., individuals caregiving for multiple people). Almost 70% of family caregivers of individuals with IDD experience compound caregiving. Yet, we know very little about compound caregiving. In this article, we highlight the importance of supporting compound caregivers by identifying research issues which highlight current challenges and future directions. Implications for research are addressed, including the need for: multi-dimensional outcome measures and longitudinal studies.

Abstract

Aging family caregivers of adults with intellectual and developmental disabilities (IDD) have unique circumstances setting them apart from the general caregiving population. Such differences include the extensive duration of the caregiving, and health concerns which manifest in the caregiver and individuals with IDD over time. Because of increasing longevity, family caregivers are likely to become compound caregivers (i.e., individuals caregiving for multiple people). Almost 70% of family caregivers of individuals with IDD experience compound caregiving. Yet, we know very little about compound caregiving. In this article, we highlight the importance of supporting compound caregivers by identifying research issues which address current challenges and future directions. Implications for research are noted, including the need for: multi-dimensional outcome measures and longitudinal studies.

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Compound Caregiving: Toward a Research Agenda

Caregiving has been the subject of considerable research for decades. The majority of extant studies focused on investigating the deleterious effects of caregiving on physical and psychological well-being, perhaps culminating in Schultz and Beach's landmark study (1999), which identified caregiving status alone as a risk factor for higher mortality. Indeed, for many years, family caregiving has been widely acknowledged as a public health issue (Talley & Crews, 2007). However, recently, a review of five population-based caregiving studies has questioned the extent to which caregiving is harmful (Roth et al., 2015). In the review, the authors countered with findings of extended longevity among caregivers finding that many caregivers report little-to-no caregiving-related strains; in addition, many caregivers report benefits of their caregiving roles. Nevertheless, one should not diminish that caregiving is a difficult endeavor for some, and remains a pervasive reality for many Americans. To illustrate, in 2017, over 41 million caregivers were estimated to provide 34 billion hours of care resulting in an economic value to the US economy of over \$470 billion dollars (Reinhard et al., 2019).

Caregiving is heterogeneous. The complexity and variety of caregiving scenarios by type of disability, severity, duration, health complications, and the relationship between the caregiver and care recipient is considerable. Unsurprisingly, caregiving scenarios which are not as prevalent in the general population remain understudied and under-funded (Haley & Perkins, 2004). Our concern is with a specific subset of caregivers—individuals who care for adults with intellectual and developmental disabilities (IDD). Indeed, aging caregivers of people with IDD have reported worse overall health (Burke & Fujiura, 2013) as well as significantly increased prevalence of several health conditions (e.g., arthritis, high blood pressure, obesity, and activity limitations, Yamaki et al., 2009).

Further, family caregivers of adults with IDD have unique circumstances setting them apart from the general caregiving population. These differences include the: extensive duration of the caregiving role, presence of health concerns which manifest over time for both the caregiver and their family member with IDD, and fears about the long-term future of people with IDD after the caregiver's death (Haley & Perkins, 2004). Specifically, while the average duration of caregiving for the general population lasts for 4.5 years, it can be a lifetime endeavor within the IDD population (Haley & Perkins, 2004). In addition, family caregivers of people with IDD are also more likely to experience intense caregiving as adults with IDD are at greater risk for developing comorbid health issues (e.g., osteoporosis, dementia) compared to the general population (Hodapp et al., 2019). Due to the need for long-term future care, there may be negative, cumulative effects of the financial burden of caregiving for family caregivers of people with IDD (versus the general population of caregivers) (Parish et al., 2004).

Perhaps most markedly, family caregivers of people with IDD are likely to be compound caregivers (i.e., individuals who care for more than one person, Perkins, 2010). In our manuscript, we define compound caregiving as providing care for a family member with IDD as well as one other family member. Specifically, for parents of individuals with IDD, compound caregiving entails providing caregiving for their offspring with IDD and at least one other family member. For siblings of individuals with IDD, compound caregiving entails caregiving for their brother/sister with IDD and another family member.

Ordinarily, one may have used the term “sandwich caregiving” to refer to parents who balance caregiving needs of a person with IDD concurrently with caregiving for one's own aging parents (Chisholm, 1999). Indeed, in the sibling literature, the term “club sandwich caregiver” is often used instead of “compound caregiver” (Meyer & Holl, 2014). However, when an

individual already has a significant caregiving role to a person with IDD, such caregiving can be compounded due to additional caregiving responsibilities for other relatives. The term “compound caregivers” was introduced by Perkins (2010) to acknowledge this important difference. Compound caregiving can affect a significant percentage of family caregivers of people with IDD (Perkins & Haley, 2010). For example, in a sample of 91 aging caregivers aged 50+ years, in which recruitment and inclusionary criteria did not mention compound caregiving status, 37% of the sample were compound caregivers (Haley & Perkins, 2010). In another study with 199 parents of adults with IDD, nearly half of the parents reported being compound caregivers (Lunsky et al., 2017). Given its definition, the term “compound caregiver” is also applicable to siblings of individuals with IDD. For example, sibling compound caregivers often support multiple family members including elderly parents, their own children, and their siblings with IDD. In a national study of 332 adult siblings of individuals with IDD, 25.90% of the sample were compound caregivers (Lee et al., 2020). Altogether, research has shown that almost 66% of family caregivers of individuals with IDD experience compound caregiving at some point during their lifetimes (Perkins & Haley, 2010). Although compound caregiving is known to occur, few studies adopt the term “compound caregivers”.

Given compound caregiving may occur for both parents and siblings, it may be necessary to examine how caregiving circumstances and, relatedly, trajectories look for different compound caregivers. Parents are often "chronic" caregivers, providing long-term caregiving. Because of their chronic caregiving roles, parents often demonstrate blunted reactions to stressors (Seltzer et al., 2010). In comparison, siblings are often planned caregivers and have shorter caregiving durations. These different caregiving durations in addition to the longer lives of individuals with IDD (Braddock et al., 2015) and the potential negative health implications of

caregiving (Schulz & Sherwood, 2008), warrant research attention for compound caregivers. To date, only two qualitative and six quantitative studies have examined the experiences of compound caregivers of individuals with IDD (Green, 2013; Lee et al., 2020; Lunsky et al., 2017; Marsack-Topolewski, 2020; 2021; Marsack-Topolewski et al., 2021; Perkins & Haley 2010; Perkins, 2010). Given the complex nature of compound caregiving research, these studies posit several areas in need of further exploration (see Figure 1). Our goal is to highlight the importance of supporting compound caregivers by understanding its population characteristics and a range of caregiving circumstances. Examining characteristics of compound caregivers of individuals with IDD is critical given that these characteristics will provide us with a better understanding of the compound caregiving population (e.g., caregiver age, income level, family size, caregiving circumstances). By characterizing the population, targeted supports can be provided. Then, we identify major issues in compound caregiving research and their implications. Last, we provide recommendations for policy and practice to promote awareness of compound caregiving. As the literature about compound caregiving has been mainly based on the contexts of the United States and Canada, many recommendations reflect North America. Throughout this paper, we compare how compound caregiving may impact parents and adult siblings.

Characterizing: Compound Caregivers, Caregiving Recipients, and Caregiving Circumstances

Compound caregivers

Parent compound caregivers

Only two studies have characterized parent compound caregivers. In a study comparing 34 compound parent caregivers of people with IDD and 57 single caregivers of people with IDD,

no significant differences were found with respect to: life satisfaction, depressive symptomatology, physical health, or mental health (Perkins & Haley, 2010). However, among compound (versus single) caregivers, there was an increased desire to place their family member with IDD into residential care. Perkins and Haley's compound caregivers were also asked to indicate which issues were most problematic as a result of their multiple caregiving roles. Caregivers reported: lack of time to pursue personal interests, inadequate help from others, and feeling stressed, emotionally drained, and physically fatigued. Similarly, Lunsky and her colleagues (2017) conducted a survey study with 199 parents of people with IDD: 96 compound caregivers and 103 single caregivers. Compound (versus single) caregivers reported significantly greater parenting burden and lower parenting mastery. However, some caregiving studies have not found any significant demographic differences (e.g., age, household income, educational background) among compound and non-compound caregivers (Lunsky et al., 2017; Perkins & Haley, 2010).

Sibling compound caregivers

Research is mixed with respect to sibling compound caregivers. Using a national dataset of 332 siblings of adults with IDD, researchers compared non-caregivers (no caregiving responsibilities), single caregivers (caregivers only for their brothers and sisters with IDD) and compound caregivers (caregivers for their brothers and sisters with IDD and at least one other vulnerable individual) (Lee et al., 2020). Compared to non-caregivers and single caregivers, compound sibling caregivers were significantly more likely to be: older, married, and have greater incomes. Further, compared to non-caregivers, compound caregivers were more likely to engage in advocacy, future planning, and report more positive relationships with their brothers and sisters with IDD (Lee et al., 2020).

Compound caregiving recipients

Parent compound caregivers

It is important to characterize the caregiving recipients of compound caregivers. In a study of 199 parent caregivers of people with IDD, compound (versus single) caregivers had slightly younger children with IDD (Lunsky et al., 2017). In addition, Perkins and Haley (2010) found that compound caregivers provided care to their family member with IDD and a variety of family members, including their spouses, fathers, siblings, aunts, and uncles. Most commonly, however, 38% of participants were compound caregiving for their family members with IDD and their own mothers.

Sibling compound caregivers

In contrast, among 86 sibling compound caregivers, almost 77% of participants provided care for their adult brother/sister with IDD and their own children while 11% of sibling compound caregivers provided care for their aging parents and their brothers and sisters with IDD (Lee et al., 2020). In addition, 12% of sibling compound caregivers provided care for their: aging parents, brothers/sisters with IDD and own children (Lee et al., 2020).

Compound caregiving circumstances

Parent compound caregivers

It is also important to clarify the circumstances surrounding compound caregiving roles. Compound caregiving episodes often occur due to health issues (Perkins, 2010; Perkins & Haley, 2010). For example, 34 parents of people with IDD reported becoming compound caregivers due to new or more serious health issues of their family members (e.g., aging parents, spouse, sibling, second child with IDD, or grandchild). Health issues included: dementia, advanced macular degeneration, cardiovascular disease, and cancer. Although there was considerable

variability in the circumstances which prompted compound caregiving roles, dementia (20.6%) was the most common circumstance (Perkins & Haley, 2010). Indeed, dementia is a common health condition for both the aging population as well as adults with IDD (Janicki & Dalton, 2000). As such, it is possible to undertake multiple caregiving roles due to chronic disease among aging parents and other family members (Heller et al., 2017).

Complicating the study of compound caregiving are the often fluid circumstances surrounding compound caregiving. Indeed, compound caregiving may involve multiple, discrete episodes over short periods of time or involve sustained caregiving for multiple individuals over decades. For example, in a case study of compound caregiving, a 60-year-old female caregiver reported four separate occasions of compound caregiving across a 17-year period (Perkins, 2010). She experienced compound caregiving for different family members (e.g., mother-in-law, father, sister, mother, and son with Down syndrome), under specific circumstances (e.g., terminal lung cancer, major stroke, breast cancer, anemia), with varying caregiving intensity (e.g., around-the-clock assistance, daily check-ins) and for changing durations (e.g., 2 months, 6 months, 9 months, 5 months). As compound caregiving is often not a one-time event, it is critical to understand the fluid nature of caregiving. Specifically, from a study with 91 caregivers who lived with their offspring with IDD, caregivers were asked to report their past, current, and future compound caregiving involvement. Altogether, 66% of caregivers reported a previous compound caregiving episode, 37% reported currently engaging in compound caregiving, and 34% anticipated becoming compound caregivers within the next five years (Perkins & Haley, 2010).

Sibling compound caregivers

Compared to the literature about parent compound caregivers, the limited research about sibling compound caregivers suggests that most compound caregiving episodes can be expected

when siblings have aging parents, brothers and sisters with IDD, and their own families. For example, in a study about adult siblings of individuals with IDD, a sibling described herself as providing compound caregiving for her 70-year-old mother, own children, and brother with IDD (Holl & Morano, 2014). Adult sibling caregivers who had children at home were less likely to provide both instrumental and emotional support to their brothers or sisters with IDD (Greenberg et al., 1999). These siblings expected that when their offspring left home, they would provide more caregiving to their brothers and sisters with IDD. Thus, caregiving circumstances may vary in relation to changing circumstances. However, it is important to note that siblings may not be able to accurately predict their future caregiving roles (Lee & Burke, 2018).

Major Issues in Studying Compound Caregiving

Despite the increasing prevalence of compound caregivers, research about compound caregivers remains under-developed. However, researchers may face several issues in examining compound caregivers. Below, we describe some of these issues, especially in the context of the caregiving literature.

Issue 1: Who should be included in research about compound caregivers?

At the most basic level, researchers need to operationally define “compound caregivers”. The definition and inclusion criteria of compound caregivers may vary with respect to the: number of caregiving recipients, duration of compound caregiving, and intensity of caregiving. Notably, compound caregiving may also look different between parents and siblings. As shown in this manuscript, there are differences between parent and sibling compound caregivers. For example, parent (versus sibling) caregivers have longer durations of caregiving. Due to their chronic caregiving roles, parents may demonstrate blunted reactions to stressors (Seltzer et al.,

2010). Future research needs to consider the different needs of parent and sibling compound caregivers.

Among the few compound caregiving studies, most researchers broadly defined “compound caregivers” (Lunsky et al., 2017; Perkins & Haley, 2010). Lunsky and her colleagues (2017) asked parents with people with IDD, “Is there someone else in the family for whom you are also the major caregiver? For example, this could be a baby or small child, an elderly parent, a spouse who is unwell, someone else with a disability.” Considering these data, Lunsky and colleagues used the number of caregiving recipients to demarcate the sample of compound caregivers; they did not include the extent or duration of caregiving responsibilities as prongs of the compound caregiving definition. Other studies have similarly used an additive approach to defining compound caregiving (e.g., Lee et al., 2020).

The purely additive approach of defining compound caregiving (i.e., only counting the number of caregiving recipients) may be overly simplistic. For example, some compound caregivers may have a greater amount of caregiving responsibilities for a long period of time while other compound caregivers may have less caregiving activities for only a short period of time. As an alternate approach to defining compound caregiving, Perkins and Haley (2010) purposefully used the broad definition (“Do you currently have caregiving tasks and responsibilities to another family member, other than your child?”). Then, participants were asked to detail their: relationships with each caregiving recipient, duration of caregiving, and history of previous compound caregiving episodes. In this way, Perkins and Haley (2010) were able to include other dimensions of caregiving in their definition of compound caregiving; notably, their inclusionary criteria required participants to: be parental caregivers aged 50+ years,

have a person with IDD age 18+ years, and have had continuous co-residence between the parent and the person with IDD.

In addition, it is important for research to address the fluidity of compound caregiving. Most prior studies were cross-sectional focused on current compound caregivers (e.g., Lunsky et al., 2017; Perkins & Haley, 2010). However, the limited extant research indicates that compound caregiving changes over time (Perkins, 2010). What about individuals who previously provided compound caregiving but are not current compound caregivers? Indeed, based on a case study described earlier in this manuscript, a caregiver reported four compound caregiving episodes across her life (Perkins, 2010). Further, each caregiving episode was distinct ranging in duration from six months to two years. Given the definition of compound caregiving, many caregivers may experience compound caregiving across their lifespans. Thus, compound caregiving research would benefit immensely from longitudinal research to address the fluid nature of caregiving.

Issue 2: Which measures should be outcome variables?

After defining compound caregiving, it is important identify outcomes of interest, especially with respect to the compound caregiver and their care recipients. Among the limited extant research, previous research has focused on the effect of compound caregiving on caregiver mental and physical health (Perkins & Haley, 2010), and family well-being or family distress (Lunsky et al., 2017). However, compound caregiving may impact a range of psychological, physical, social, economical, and caregiving variables. Therefore, it is essential to include multidimensional measures of compound caregiving outcomes.

Mental and physical health. In the general caregiving literature, the potential negative health implications of single caregiving have been discussed (e.g., Pinquart & Sörensen, 2003;

Schulz & Sherwood, 2008). Indeed, previous research has found that caregivers are often at-risk for worse emotional and physical health (e.g., stress, depression, lower level of subjective well-being, and worse physical health) (Pinquart & Sörensen, 2003). Consistent with the research about the general population of caregivers, many studies of caregiving for individuals with IDD also report a greater risk in relation to mental and physical health (Williamson & Perkins, 2014). Specific outcomes for which caregivers of people with IDD are at greater risk include emotional health (e.g., anxiety, depression or guilt) and physical health (e.g., chronic fatigue, sleep deprivation, chronic physical ailments such as back and shoulder pain) (Murphy et al., 2007). Further, compound caregiving may have a negative impact on: stress resilience (i.e., effectively coping with stressors) and coping abilities (Perkins, 2010).

Notably, given the chronic nature of caregiving, it is important to determine whether health outcomes (e.g., stress) differ among compound (versus single) caregivers. In the seminal article by Pearlin et al. (1990), researchers suggested a conceptual caregiver stress model. In this model, there were four domains of caregiving stress: background and contexts, primary stressors, secondary role strains, mediators, and outcomes. Compared to chronic caregiving, compound caregivers may have multiple primary stressors (e.g., caregiving recipients) which further influence secondary role strains (e.g., family conflict, economic or social constriction). Given the impact of single caregiving on mental and physical health, extensive research about mental and physical health outcomes is needed about compound caregivers.

Social outcomes. From the gerontology literature, multiple caregiving roles often correlate with a reduced social network (Bailey et al., 2010; DePasquale et al., 2016; Perkins, 2010; Scott et al., 2006). For example, compound caregivers of individuals without IDD for more than two vulnerable individuals (i.e., child and/or elder care) report greater work-related

strains and poorer partner relationship quality compared to single caregivers (DePasquale et al., 2016). Due to prolonged caregiving, compound caregivers may have limited or no break for themselves. Accordingly, compound caregivers may need to continuously negotiate personal role boundaries with their care recipients, to the extent possible.

Despite the potential negative impact of compound caregiving on social outcomes, building stronger social network may be the key to enhance caregiver resilience and overall quality of life outcomes (Perkins, & Hewitt, 2016; Perkins & LaMartin, 2012). Since the 1990s, research has suggested that caregivers who had larger and more satisfying social relationships reported better morale and less caregiving stress (e.g., Greenberg et al., 1997). Thus, research is needed to examine social support among compound caregivers.

Economic outcomes. In the general caregiving literature, research suggests that many family caregivers experience financial demands due to their caregiving roles (Wolff et al., 2016). For example, almost 38% of family caregivers reported experiencing a moderate-to-high degree of financial strain as a result of providing care (Williamson & Perkins, 2014). Although caregiving responsibilities vary, especially within the literature about caregiving for individuals with IDD, one of the most frequent caregiving responsibilities includes meeting the financial needs of care recipients (Burke et al., 2012). For example, many adults with IDD do not have substantive employment (Butterworth et al., 2015). Accordingly, caregivers may need to pay out-of-pocket for medical and other services (Anderson et al., 2018). In addition, having a family member with IDD likely has an effect on caregiver employment. In a study of 165 mothers of adults with IDD, mothers reported that, due to their caregiving roles, they were less able to work and, correspondingly, had little income (Parish et al., 2004). Further, many parent caregivers of individuals with IDD reported various effects of caregiving on their economic outcomes

including: the need to reduce their work hours and the frequent need to take time off from work (Thyen et al., 1999). Given the impact of caregiving on economic outcomes, compound caregivers with multiple care recipients may face even worse financial hardships.

Caregiving appraisal. Although caregivers are often characterized by the wear-and-tear effects of caregiving (Townsend et al., 1989), caregiving can also be a rewarding experience (Heller et al., 1997). Research suggests using a positive psychology framework to identify positive aspects of being a family member of an individual with IDD, including rewarding aspects of caregiving (Dykens, 2006). To address this, within the context of caregiving, researchers may measure caregiving appraisal, “the cognitive and affective responses that caregivers have in reaction to the demands of caregiving.” (Heller et al., 1997, p. 338). According to Burke and Heller (2016), the caregiving appraisal construct includes: caregiving burden (i.e., impact of caregiving upon opportunities, finances and leisure), caregiving satisfaction (i.e., feeling rewarded by the caregiving role), and caregiving self-efficacy or caregiving mastery (i.e., feeling competent in caregiving skills).

It is unknown whether multiple caregiving responsibilities impact caregiving appraisal. Among the limited compound caregiving literature, the research is mixed (Green, 2013; Lunsky et al., 2017). For example, Lunsky and her colleagues reported that compound (versus single) caregivers reported significantly: higher burden and lower mastery. Future research should consider how compound caregiving may impact caregiving appraisal, including positive and negative aspects of caregiving.

Issue 3: What are potential mediators and moderators of compound caregiving outcomes?

While it is critical to accurately measure outcomes of compound caregiving, researchers should also identify mediators or moderators which may impact such outcomes. Notably, based

on prior research in the general population of caregiving, mediators and moderators may include: race, gender, income, parent mental health, parenting stress, problem-solving strategies, coping style, and social support (Kim et al., 2019; Marsack-Topolewski, 2020; Ownsworth et al., 2010). For example, in a survey study with 1772 compound caregivers of individuals without IDD, Kim and her colleagues (2019) reported that race/ethnicity could be a moderator for compound caregiving outcomes. Specifically, African-American compound caregivers had poorer self-rated health than non-compound caregivers while other racial compound caregiver groups had better self-rated health. Likewise, if compound caregivers actively engage in problem-solving strategies, they may have less caregiving stress or they may be less at risk to have depression. With research about sibling caregivers for adults with IDD, race/ethnicity has also been found to be a moderator of caregiving with African American and Latino (versus White) siblings of individuals with IDD being more likely to become caregivers (Sonik et al., 2016). Researchers should consider whether the same moderators exist for compound caregivers.

In addition, the characteristics of individuals with IDD may mediate compound caregiving outcomes. For example, maladaptive behaviors could be a potential mediator given its impact on caregiving burden (e.g., Eisenhower et al., 2009; Lovell & Wetherell, 2015; Seltzer et al., 1991). Indeed, maladaptive behaviors may influence a range of caregiving outcomes including caregiver health and quality of life (Khanna et al., 2011). However, other potential mediators may improve caregiver outcomes. For example, if compound caregivers have strong social support, such support could buffer against problem behaviors (Khanna et al., 2011) and lead to lower: caregiver anxiety, depression, and stress (Sharpley et al. 1997). Given the potential relations among several variables and caregiving outcomes, it is necessary to explore mediators and moderators in research about compound caregiving.

Notably, when considering mediators and moderators, it is critical to explore whether there are different mediators and moderators of outcomes for parent (versus sibling) compound caregivers. Some mediators, for example, may be the same for parent and sibling compound caregivers. For example, maladaptive behavior worsens parent health (Eisenhower et al., 2009; Lovell & Wetherell, 2015; Seltzer et al., 1991) as well as correlates with poor sibling relationship quality (Hodapp et al., 2010). However, there may also be unique mediators and moderators among parent and sibling compound caregivers. For example, unlike parents, the number of siblings in the family may impact compound caregiving. Indeed, the number of siblings does seem to impact caregiving for one individual with IDD (Burke et al., 2012). Thus, future research needs to carefully consider mediators and moderators for these different groups.

Issue 4: How can longitudinal trajectories of compound caregiving be measured?

Caregiving can be a life-long commitment. In the traditional model of caregiving, researchers often perceive that there is a cumulative effect of caregiving on health over time (Schulz et al., 1990). Specifically, caregiving may “wear and tear” on caregiver health over time. However, over time, caregiving roles and stressors are likely to alternate between being stable and dynamic. Seltzer and Li (2000) described the caregiving role as a career which changes across life courses. For example, different caregiving dynamics are reported during caregiving transitions such as: entry into the caregiving role, out-of-the-home placement of the individual with IDD, and bereavement of family members. Although caregiving for adults with IDD is often a lifelong endeavor, other caregiving roles (e.g., caregiving for ill parents, spouse, or children) may be unplanned. Most importantly, caregivers may experience these caregiving transitions with different intensity based on the relationship with care recipients and the context.

Interestingly, compound caregiving trajectories may differ between parent and sibling caregivers. While parent caregivers assume lifelong caregiving responsibilities for their offspring with IDD, sibling compound caregiving has shorter durations. Further, such different trajectories may also reflect different “push” and “pull” factors. For example, among the sibling literature, push and pull factors to caregiving include: gender, proximity, emotional closeness, having children at home (Greenberg et al., 1999). Such factors may differ for parent compound caregivers. Therefore, to fully understand caregiving across the life span, longitudinal investigation is needed and would allow for the study of the effects and outcomes that occur between and during compound and non-compound caregiving, and what residual effects may arise (Perkins & Haley, 2010). Even more rigorous would be to simultaneously study dyads of both caregiver and their family members with IDD.

Researchers also need to consider developmental transitions for both the person with IDD and the caregiver. Indeed, longitudinal research will shed light on how compound caregiving contexts may look different with respect to: caregiving recipients, caregiving competence, and the impact of caregiving. In population research, Carter and McGoldrick (1988) identified six stages in the life cycle of families: single young adults; the joining of families through marriage; families with young children; families with adolescents; launching children and moving on; and families in later life. Longitudinal research across each stage may help pinpoint stressors and facilitators among compound caregivers. For example, among families in their last stage, compound caregivers may be preparing to address their own aging as well as the aging of the family member with IDD. At this point, siblings may step into compound caregiving roles to provide support to both their parents and their brother/sister with IDD (Authors, in press). By

having longitudinal research, researchers can identify the presence or absence of particular challenges among caregivers thereby informing needed interventions for compound caregivers.

Issue 5: What are the perspectives of compound care recipients?

Most family caregiving research is based on the assumption that caregiving is uni-directional: caregiving is the provision of care by family members to the person with IDD. Yet, in many cases, the adult with IDD provides support to caregivers as well as other family members (i.e., siblings) (Kramer et al., 2013; Perkins & Haley, 2013). Such reciprocity in roles may be particularly salient among individuals with IDD and their elderly parents, who have growing support needs as they age. Indeed, the caregivers reported greater caregiving rewards when there is reciprocal relationship with care recipients (Raschick & Ingersoll-Dayton, 2004). Unfortunately, to our knowledge, only four studies have examined caregiving reciprocity in the IDD field (Heller et al., 1997; Kramer et al., 2013; Perkins & Haley, 2013; Williams & Robinson, 2001). For example, Heller and her colleagues (1997) reported that adults with ID become companions for their aging parents as well as help with house chores. These studies suggest that reciprocity is relevant in caregiving for individuals with ID.

Accordingly, it is critical to explore the perspectives of individuals with IDD in compound caregiving research. At the most basic level, research is needed to understand the perspectives of individuals with IDD in relation to their relationships with their caregivers (Walker et al., 1992) and caregiving appraisal (Dwyer et al., 1994). Although not explored among individuals with ID, when elderly care recipients see themselves as active relationship participants, they were significantly more likely to have positive: self-feelings and social interactions with their caregivers (Walker et al., 1992). It is unknown whether the nature of the caregiving relationship and related outcomes may be impacted by compound caregiving. By only

including the perspective of the compound caregivers, research is missing half of the story—the perspectives of care recipients themselves.

Implications for Policy and Practice

Formal Supports for Individuals with Disabilities and their Families

Globally, formal supports for individuals with disabilities must meet the needs of compound caregivers. In the U.S., for example, compound caregivers need to be addressed by Home and Community-Based Services (HCBS) Medicaid waivers. Such waivers can provide various types of support including group homes in the community, respite for family caregivers, and personal support workers to assist with recreation and leisure activities. Unfortunately, 43 states have waiting lists for HCBS Medicaid waivers (Braddock et al., 2015). Such waiting lists vary in size and duration with some waiting lists only requiring a few days to receive services and other waiting lists lasting decades (Lakin et al., 2015). As a way to determine who receives the limited HCBS Medicaid waivers, many states have priority categories wherein individuals with certain characteristics (e.g., older individuals) or circumstances (e.g., homelessness) are prioritized first for services. Although it is our position that there should be no waiting lists for any individual with IDD, we also recognize the systemic barriers and complexity in achieving this goal. Thus, while there continue to be priorities in HCBS Medicaid waiver waiting lists, we suggest including “compound caregivers” as a priority. Other jurisdictions should also consider prioritizing compound caregivers for formal services.

Relatedly, formal services need to be flexible to address the needs of compound caregivers. Given that caregiving is fluid (Perkins, 2010), policies also need to be flexible such that they can be responsive to the changing needs of caregivers. To assess for the needs of caregivers, family assessments may be helpful (Feinberg, 2007). Such assessments, if provided

annually, will help identify the changing needs of caregivers. Unfortunately, in the United States, only a third of states include family caregiver assessment in HCBS Medicaid waiver evaluations (Kelly et al., 2013). Moving forward, ongoing assessments of caregiving needs may help inform how adult services can be responsive to caregivers.

Paid Caregiving

Policy should enable caregivers to be paid to provide caregiving. Altogether, in the U.S., caregivers provide \$375 billion dollars worth of care and subsequently, savings to the government by not having professionals provide such care (Houser & Gibson, 2008). The economic cost of providing caregiving may result in many parents of adults with (versus without) IDD engaging in fewer hours of employment (Parish, 2013) and, subsequently, having less disposable income (Emerson, 2007). In some states, caregivers are paid to provide caregiving support (e.g., Burke et al., 2015). By paying family caregivers, the financial burden may be reduced for families of individuals with IDD.

Notably, caregivers should receive commensurate financial support when engaging in multiple caregiving roles. In a report about compound caregivers, the caregivers reported spending an average of 52 hours a week on caregiving responsibilities (Perkins, 2010). Thus, the number of hours may be far greater than the typical work week. Relatedly, the financial support is not only about the pure cost of paying an individual but also about providing needed benefits and vacation/sick leave. Like most of the workforce, compound caregivers will need health insurance and paid time off. Policy across jurisdictions (not just the U.S.) should address these needs if family members continue to be turned to as caregivers for individuals with IDD (Swenson, 2005).

Comprehensive Coordinated Respite care

Respite care can be critical in supporting the health and well-being of caregivers (Perkins, 2010; Whitmore, 2016). Yet, respite may fall short when considering compound caregivers. Most respite hours are attached to an individual with IDD—not to the caregiver. Thus, for example, a compound caregiver may receive respite for their child with a disability but not for their brother/sister with IDD. Without providing respite to both individuals with IDD, the caregiver does not receive meaningful respite. Practitioners should consider creative ways to combine services such that respite can be consolidated for compound caregivers (Perkins, 2010).

Relatedly, policies about respite care may need to be more responsive to the needs of compound caregivers (Perkins, 2011). Perkins highlighted U.S. legislation such as the Older American Act's National Family Caregiver Support Program and the Lifespan Respite Care Act of 2006, that would benefit from expanding eligibility and funding. For example, caregivers of adult children with IDD are not eligible to receive respite care under the National Family Caregiver Support Program thus limiting its effectiveness and outreach to some compound caregivers. Policies need to be geared and funded to adequately service compound caregivers. Other countries may also need to ensure respite services and the legislation that guides their implementation have the flexibility and funding to recognize and appropriately support compound caregivers' complex and changing needs. To adequately assess compound caregivers' needs, Williams and Perkins (2014) suggested a comprehensive caregiver assessment using the ecological model. In their proposed assessment, they addressed a range of caregiver domains such as decision making, compound caregiving, family network, informal or formal support, future planning, health-related quality of life, life satisfaction, and service utilization.

Conclusion

The current paper synthesizes the literature about compound caregivers in North America and suggests directions for future research. Across compound caregivers, their characteristics, care recipients, and circumstances may significantly vary, especially between parent and sibling compound caregivers. Given the varied characteristics of compound caregivers, it is necessary to consider a few major issues (e.g., the definition of compound caregiving, potential mediators and moderators of compound caregiving, outcome trajectories, and the perspectives of caregiving recipients) when exploring compound caregiving. Due to the limited research, it is unknown whether compound caregiving for people with IDD looks different from traditional caregivers. Further, the current literature only highlighted compound caregivers in the U.S. and Canada. Future comparative studies with compound caregivers in other non-North American countries may be insightful, as the evidence base expands. By intentionally exploring the roles of compound caregivers, policies and practices can be revised to meet their needs.

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Figure 1.

Considerations for compound caregiving research

Who is compound caregiver and care recipients?	When does compound caregiving occur?	How does compound caregiving impact?
<ul style="list-style-type: none"> • Characteristics of compound caregiver • Characteristics of compound care recipients 	<ul style="list-style-type: none"> • Marriage • Families with young children • Families with adolescents • Launching children and moving on • Families in later life 	<ul style="list-style-type: none"> • Mental and physical impact • Social impact • Economic impact • Caregiving impact