Aging Together: Caring Relations in Families of Adults With Intellectual Disabilities

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Abstract

Purpose of the Study: To examine the dynamics of caring relations in older families that include an adult with Intellectual Disabilities (ID). To date, there has been very little research exploring the experiences of aging families of community-dwelling adults with ID.

Design and Methods: An exploratory, qualitative study was conducted in British Columbia, Canada. Eight participants were recruited through purposive sampling. In-depth, semi-structured interviews were conducted to explore the experience of aging concurrently with a community-dwelling relative with ID. Data were analyzed using a thematic approach.

Results: Three main themes emerged: (a) Recognizing the Changes of Aging, (b) Strengthening Connections, and (c) Planning for the Future.

Implications: Aging concurrently with a community-dwelling relative with ID is a unique experience for older adults and challenges traditional views of familial caring relations. These relationships are characterized by evolving patterns of care and exchange. There is also a sense of urgency to securing future care arrangements for the adult relative with ID. Advanced care-planning is complicated by the adult with ID’s understanding of death and dying. Family caregiving policies and practices that take into account the complexities of these relationships are needed.

Keywords: Intellectual Disabilities, Informal caregiving, Qualitative research, Life-course perspective

Changes in practices and policies for adults with Intellectual Disabilities (ID) have evolved over recent decades (Innes, McCabe, & Watchman, 2012) leading to a shift from segregated residential or institutional care to a person-centered approach, with an emphasis on inclusion and community living. This shift has been instrumental in improving the quality of life of people with ID, providing them with greater choice and control over their lives (Innes et al., 2012). A large number of adults with ID, who live in community settings (e.g., private homes or group homes), are cared for primarily by parents and other family members (Gilbert, Lankshear, & Petersen, 2008; McConkey, 2005). In the United States, approximately 2.79 million of the 4.56 million people with ID live with family caregivers (Braddock, Hemp, & Rizzolo, 2004), and more than 25% of adults with ID live with parents aged 60 or older (President’s Committee for People with Intellectual Disabilities, 2004). In Canada, family members are the main source of support for almost 80% of adults with ID (Canada Housing and Mortgage Corporation, 2006) and approximately 50%–60% live with family members (Weeks, Nilsson, Bryant, & Kosma, 2009).

In the context of significant improvements in social and health conditions leading to a dramatic increase in...
life expectancy over the past decade (Bigby, 2002; Hole, Stainton, & Wilson, 2013; Stainton et al., 2006), aging with ID has emerged as an important area of research (Bigby, 2002; Innes et al., 2012). However, while there is a body of literature about familial care work for children with ID (Haley & Perkins, 2004), the intersection of these areas—aging and familial care work for adults with ID—remains quite limited. Given the reliance of health and social service systems on family involvement in the lives of these adults, the concurrent aging of both groups has implications for policies and practices. The aim of this study, therefore, was to examine the dynamics of caring relations in the families of community-dwelling adults with ID as they experience the aging process together.

**Literature Review**

Within the family caregiving literature, there is a small body of research about caring for an adult relative with ID. While it may be assumed that care responsibilities lead to increasing stress over the lifetime of a family member, research suggests that caring for an individual with ID is predicated on a complex mix of contextual and personal variables. A study conducted by Walden, Pistrang, and Joyce (2000) found that the relative with IDs’ care needs, coupled with the availability of informal supports, were associated with quality of life of family members. Further, parental appraisals of aging and stress associated with caring for an adult-child with ID was found to mediate the relationship between health and depression (Minnes, Woodford, & Passey, 2007). Parents have emphasized the importance of informal activities and supports, such as maintaining social connections, building networks, having a stable environment to live in, and being able to engage in the day-to-day activities that the individual enjoys, as key aspects of supporting aging adults with ID (Bowey & McLaughlin, 2007; Hole et al., 2013; Weeks et al., 2009). These findings contradict the assumption that formal services alone enable families to continue to care for an aging relative with ID (Walden et al., 2000).

Research has also identified how the care these families engage in is distinct from other familial caregiving relationships, such as adult children caring for aging parents. While family members can and do engage in instrumental or physical care activities, such as providing food, or helping their relative with Activities of Daily Living (e.g., getting dressed), there is an additional requisite investment of emotional and organizational labor which is less obviously discernable. Referred to as “invisible care” (Grant, 2007), it is perhaps the most prominent area of support provided by family members of aging adults with ID who live with relatives (e.g., parents) or in other community care facilities (e.g., group homes). Broadening the definition of what constitutes care highlights the management of such “hidden” care activities and the significant personal investment of the family members (Grant, 2007).

Studies have also moved away from a unidirectional model of caregiving to highlight the dynamic and subtle interplay of caring relations between family members and adults with ID. Many parents, in particular, come to rely on their adult-child for support. Parents speak of reciprocal exchange as they depend on their adult-child with ID for practical tasks and emotional support (Bowey & McLaughlin, 2007; Grant, 2007). There exist interpersonal rewards for these parents, such as a sense of gratification of seeing their adult-child happy and feeling a close emotional bond. Further, older parents, compared to new or younger family members, may be more certain of their expertise and experience and ability to handle situations, leading to satisfaction at an intrapersonal level (Grant, 2007). These rewards can also extend into the public domain, as parents, driven by their frustration with policy and service deficits, begin to engage externally with their communities, other families, and independent service sectors.

At the same time, as parents age, they may be less able to provide the type and amount of care needed by their adult-child with ID. Factors contributing to this situation include: being physically unable to provide a high level of personal care, needing to care for an ageing spouse, being older than 75 years; having greater stress levels, having limited income, and/or the death of the caregiver (Bowey & McLaughlin, 2007; Dillenburger & McKerr, 2009; Weeks et al., 2009). The fact that individuals with ID are themselves aging poses a challenging arrangement, as it may be difficult for them to find other sources of support to replace the type of care previously provided by their parent.

Even though families may acknowledge that theirs will be a lifetime of exchanging care, many have not engaged in formal future planning activities (Bowey & McLaughlin, 2007; Hole et al., 2013; Ryan, Taggart, Truesdale-Kennedy, & Slevin, 2014; Weeks et al., 2009). A lack of future planning can contribute to inappropriate and rushed care when a parent or family member is no longer available. As a result, some adults with ID are placed in nursing homes designed for the frail elderly, even though they are “... poorly matched to these settings and do not fit the average resident profile and needs” (Bigby, 2010, p.10). A lack of engagement with formal future planning may be attributable, in part, to aging family members’ desire to protect adults with ID from their relative’s mortality and is also reflective of informal and formal barriers that result in a disconnection from services and supports (Bigby, 2002; Bowey & McLaughlin, 2007; Hole et al., 2013). Furthermore, many aging parents take the view that they alone can provide proper care for their adult-child with ID (Gilbert et al., 2008), a belief that may result from their experiences with low-quality services or institutionalization when their child was younger.

In sum, caring relations between aging family members and their relative with ID are markedly different from “typical” caregiving relationships. Despite the ongoing shift from institutionalization to community living, there is
little research exploring the unique caring relations in aging families that include adults with ID, and most of the existing studies have focused exclusively on parent–child dyads living together at home. There is a need for research to take a broader view to explore a more diverse range of family relationships and living situations. Such evidence could be used to inform policy and practices to support successful aging. Therefore, the purpose of this study was to extend understanding of the unique experiences of families aging together in the community, when one member is an adult with ID. The research question guiding this inquiry was: what are the experiences of family members who are aging concurrently with their relative with ID?

Methods

Research ethics approval was obtained from the University of British Columbia’s Behavioural Research Ethics Board. The study employed an exploratory, qualitative approach (Sandelowski, 2010; 2009) and was conducted with individuals living in a large urban area of British Columbia, Canada. We sought a purposive sample, that is, participants who were able to provide rich data and who represented a range of familial relationships with aging adults with ID. Inclusion criteria were therefore broad: participants had to self-identify as a family member who had provided care for a community-dwelling adult with ID, and the relative with ID had to be aged 40 years or older. Informational flyers were posted at local organizations supporting adults with ID and potential participants contacted the researcher to obtain more information about the study and to ascertain their eligibility. Family members who consented to participate in the study were invited to ask their relative with ID to also participate in the interview, and one mother chose to do this and her daughter assented to participate. Because the interviews focused on their caring activities, most of the family members chose not to have their relative with ID present.

Eight family members participated in this study, representing six families (in one case, the adult with ID also participated in the interview). Five of the participants were parents (three mothers, two fathers), one was a sister, one was a brother-in-law, and one was a family member “by choice” who had met her relative through a home-sharing situation. The average age of participants was 77 years, with a range of 64–86 years old. Within 1 year of study participation, the two fathers died, reflecting the tenuous nature of these caring relations in aging families. Most of the relatives with ID lived in group homes, one lived in an independent apartment, while another lived with their family member. In one family, the relative with ID had recently died, however, the participant had a great desire to be in the study to share her experiences.

Data were collected between April 2009 and March 2010 through in-depth, semistructured interviews that were characterized by interpersonal dialogue between the researcher and the participant (DiCicco-Bloom & Crabtree, 2006). Six interviews were conducted, as families with multiple participants chose to be interviewed together. The interviews lasted about 1 hr and explored the family members’ patterns of caring relations with their relative with ID (e.g., types of care provided and received, as well as supports [or lack thereof] from health and social service agencies). Demographics were also collected as part of the interview process. Digital recordings of the interviews were transcribed verbatim, these transcripts were used for data analysis.

Data analysis occurred concurrently with data collection to allow for an inductive process. Data were entered in NVivo software for the purpose of data management and organization. Guided by the research questions, data were then systematically categorized and coded, following a cycle of comparison between “old” and “new” pieces of data (Boeije, 2002). Analyses employed a life-course perspective, which encourages a focus on patterns of individual well-being and development with an emphasis on the effect of specific contextual phenomena, including relationships, on life outcomes (Esbensen, Seltzer, & Krauss, 2012; Stowe & Cooney, 2015). A major tenant of this perspective is that no single period of life dominates the continuous process of development. This theoretical lens challenges the researcher to conceptualize the importance of the past, present, and future development of an individual with ID and their family (Esbensen et al., 2012). Following initial analysis, emerging findings were presented to six of the eight family members at a knowledge translation workshop to ensure the findings were reflective of their experiences. Their feedback was then integrated into the analytic process to generate the study themes.

Findings

The main themes of this study reflect three key aspects of the caring relations that exist in families that include an adult with ID as family members age together in the community. These themes are illustrated below: (a) Recognizing the Changes of Aging, (b) Strengthening Connections, and (c) Planning for the Future. Although the family members reflected a range of familial relationships and living arrangements with their relative with ID, all were engaged in similar care activities. Specifically, none of the family members were providing “hands-on” care, rather their main care activities were providing socio-emotional support and case managing health and social supports.

Recognizing the Changes of Aging

Participants were experiencing changes associated with aging that had significant impact in many areas of family life. They reflected on their own needs and how these evolved as they grew older. They also recognized aging in their relative with ID, and how it was affecting their care
needs. Further, family members described how aging was changing the roles they had in their communities, particularly their political activism related to civil rights for people with ID.

Aging family members were acutely aware of their own aging process, and the potential consequences of the care work they undertook with their relative with ID. Some of the changes were actually consequences of a lifetime of caring, as a mother described, “I had developed a serious back problem which was clearly related to the carrying and the care.” Similar to previous research, another mother explained how her relationship with her daughter was moving towards a more reciprocal model of caring, “And as mobility is declining and I’ll say ‘Oh, my aching back.’ And she’ll say ‘Oh, I’ll get it mom!’ you know? So, that’s good when she’s home. But I don’t rely on that. But I’ve seen other moms relying on it.” (P2).

Others identified an internal tension with the need to decrease on their care activities, so family members found ways to stay involved as much as possible, while shifting away from the day-to-day physical demands of caring to providing more socio-emotional support, as a father described, “We do it as much as we can because we want to, we want to be our daughter’s…we want to have that relationship as long as we can.” Several family members described this shift, where their relative had moved into supportive housing (e.g., group home, home-sharing) and instead of providing physical care, their care activities had become much more focused on case management of their relative’s medical and social needs, for example attending medical visits, and visiting, either by phone or in person.

In addition to acknowledging the impact of their aging bodies on care activities, participants also reflected on the developmental transitions occurring in their family life. For example, families were very cognizant of the socially constructed context of caring for a family member with an ID, which was characterized by choices around moving their relative with ID into an institution or living with them in the community. With aging, those who had lived together had to reconsider their situation, now anticipating that their relative with ID would outlive them. A mother described how this situation was confronting many of her peers, “I’ve met families, who have kept their kids at home, and now they’re getting on and they’re worried about the reality of what’s going to happen when they go.” And she went on to talk about her own experience, in reference to her daughter, an important part of her role was to strengthen his connections with the group home staff by explaining his behaviors in the context of his life history. She explained how a behavior that was sometimes perceived as problematic by staff had its origins in his childhood interactions with their parents, “emotional needs need to be met, but I gotta tell you, we ever had to, but we knew for her sake we had to.” To alleviate some of the difficulty of separating from their relative with ID, family members had developed patterns of visiting, as this father illustrated, “Twice a week. We have her on Sunday for dinner, and on Wednesday for dinner, and of course she comes on long weekends and she’ll have a week or so with us at Christmastime”.

A valued aspect of care activities for many of these family members was their high degree of involvement in political advocacy related to civil rights for people with ID. Several of the parents in the study were instrumental in advocating for community living for their children during the 1960s, marking a shift away from institutionalization (McCallum, 2001). A mother described the genesis of the community living movement in their area, “It was founded in ’70… we got together with another group of parents back in ’74, or ’75 I guess, but anyway we organized an organization that was focusing more on the physically handicapped rather than the developmentally…”. Many parent participants remained politically active in the area of disability rights into their old age and reflected on the consequences of aging on this work. A mother described the evolution of a group she founded: “I also ran a group for over twenty years, and we had to shut it down because they’re all getting my age and we’re getting too unable. You know there’s only half a dozen of us left now. But that was a unique experience, getting to find out what really happened [in the institutions], trying to have some influence...”. The sister and brother-in-law participants were currently supporting their relative in a class action suit related to time spent in an institution. Overall, family members viewed their political activism as an extension of their familial role. However, in light of their aging and declining stamina, many of them had to take a step back from their advocacy work.

**Strengthening Connections**

As families aged together, there was an emphasis on fostering connections that could supplement or replace their care activities, particularly for aging parents facing their own physical decline and mortality. These connections focused on helping their relative with ID strengthen relationships with siblings and develop peer friendships, while also shifting care responsibilities to formal care providers and other community-based supports.

Aging family members viewed the creation and maintenance of informal connections, particularly with siblings, as an important source of care. A father reflected on the bond between his adult children, “She’s very lucky, you know, lucky to have somebody. You know if she didn’t have [brother], she’d be different.” A sister reflected on the relationship she had built with her brother, from whom she had been separated for decades while he lived in an institution. After he moved into a group home, she saw this relationship become integral to her everyday life saying “it [relationship] has to become part of my routine.” She and her husband had daily phone calls with her brother and visited in person twice per week. For the sister, an important part of her role was to strengthen his connections with the group home staff by explaining his behaviors in the context of his life history. She explained how a behavior that was sometimes perceived as problematic by staff had its origins in his childhood interactions with their parents, “emotional needs need to be met,
and behavioral concerns arise because of that. And this is what’s so important to him, is just like all of us I guess, looking for affection, love, some sort of connection to people. He’s had his emotional maturity stunted at a certain age, because even now he still wants to have you hug him from behind, like this [demonstrates], he’ll turn himself around so that you can put your arms around him. This is something my parents used to do.” Family members also viewed part of their role to foster connections with friends and peers. Some saw this as a benefit of living in a group home. A father explained “the plus for us was that she had an incredible widening of circle of friends, which I don’t think we could have provided to that extent if she had been at home, you know?”

As aging family members became increasingly aware of their own aging bodies and mortality, some were making a conscious effort to shift care activities to formal providers. A mother said, “I’m in the background now” when describing her situation. In anticipation of being less available to visit, a father described how he and the staff at his daughter’s group home were approaching the situation: “They [staff] don’t want me to muck up the routine, the daytime routine. That’s important that routines stay predictable for her, if that’s the right word. She’s got to be able to predict what happens.” While their relatives with ID remained central to their lives, these aging family members were also conscious that they were approaching a time when they would no longer be able to provide any care for them. Therefore, they were in a process of shifting care activities, and as keepers of their relative’s biographical history, were focused on transferring this valuable information to formal care providers to ensure continuity of care.

Planning for the Future

Future planning was at the forefront of many of the participants’ minds, particularly the aging parents who were in their 80s and 90s. They had already experienced losses of other family members, as this mother described “[Aunt] used to come for Christmas dinner, she died, she can’t come to Christmas dinner anymore. And there’s aunts and uncles and my brother and so on, and they’re gone, so it stands to reason that if we get old enough we will go too. But we’re trying to postpone the day as long as possible.”

Others recognized their own decline, as explained by this father:

Interviewer: “What have you found most difficult as you get older in continuing to be part of [daughter’s] life?”

Participant: “Well, I’d like to keep going and I’m having difficulty keeping going, and everybody’s telling me to cut-down, cool-off, slow-down kind of stuff and I say, ‘Well, I can’t.’ She’s expecting me, she would get mad as hell if I don’t show up like I’m supposed to.”

This father expressed a concern confronting many of the parents, that is, their own mortality and the difficulty of transitioning from their current level of involvement to something else. This situation also reflected concerns about “letting down” the adult with ID, who may not fully understand why their family member was no longer as present as in the past. Further, even though his daughter lived in a group home so that all of her physical care needs were met, he was still concerned with how her socio-emotional needs were going to be met in the future, which was a main care activity for all of the family members in the study.

In an interview where the mother and daughter with ID were present, this exchange took place:

Mother to Interviewer: Now I’m deliberately falling back on purpose, because mom isn’t around forever.

Daughter: I’m not going to let you go.

Mother to Interviewer: And the more independent she can be, and the more facets she can bring into her life, the easier it’s going to be to keep her routine going, and stay healthy herself.

Daughter: I’m not going to let you go.

Mother to Daughter: Well... is that right? Okay.

Daughter: No, I’ll never, never let you go.

While this exchange may be common to any conversation between an aging parent and their adult-child, the conversation surrounding this exchange made clear that the daughter did not understand the permanency of death and her mother struggled with repeatedly having this conversation. Therefore, rather than being able to engage in this developmental task of aging, some family members avoided future planning or did it in ways that they perceived had the least impact on their relative with ID.

Discussion

The findings from this study illuminate the unique, complex, and evolving caring relations in families of community-dwelling adults with ID as they age together. Drawing from a life-course perspective, this study illustrates the dynamic nature of the caring relationships embedded in and shaped by individual and family life history and also draws attention to the historical and social circumstance that impact these interactions (Esbensen et al., 2012). Viewing these relationships through this perspective, we found that these families are in a time of late-life transition following a lifetime of evolving caring relations. Aging parents and relatives were increasingly cognizant of their own aging process and the implications for their capacity to continue providing care. This led them to put effort into strengthening connections for their relative with ID with both informal (family and friends) and formal (social service agencies) sources of care. They also focused on continuing to shift their care activities from providing physical support to focusing on
socio-emotional support and transferring their intimate biographical knowledge of their relative with ID to others who could provide care in the future. A challenge for these families was engaging in conversations and planning around end-of-life and depended to a certain extent on their relative with ID’s understanding of death and dying and their emotional readiness to live without their main care provider.

Previous research in this area, while limited, supports our findings of the unique characteristics of aging families that include an adult with ID. A first characteristic is the nature of the flow of caring activities. Rather than the majority of care flowing from offspring to parents, the parents/older relatives provide care for their relative with ID. A second characteristic way in which these families differed from typical caregiving dyads was that care was less unidirectional; in particular, as parents aged and experienced greater disability, care activities became more of a dynamic exchange. A third characteristic was reflected in how caring relationships in these families had evolved over the life-course, and this had implications for the type of support they were seeking in old age. The characteristics of caring relations in families that include a community-dwelling adult with ID have implications for how clinicians should assess patterns of care exchange and ensure adequate supports are in place when one member of the relationship is no longer able to contribute in the same way.

This study also extends previous research in that previous studies mainly focused on the experiences of aging parents whose children lived with them. Our study was inclusive, and arguably more reflective, of the increasing diversity in these aging families, and included a variety of family relationships (e.g., parents, siblings, in-laws, “family by choice”), and was reflective of the growing options of community living for aging adults with ID (e.g., independent living, group homes, homesharing). Yet despite this diversity, we found that the family members were exclusively engaged in the caring activities of providing socio-emotional support and case management and were no longer providing “hands-on” physical care, regardless of their familial relationship or living situation. Further, they shared concerns in common, particularly around future planning, regardless of the level of physical support care in their relative’s living situation. Hence, this study extends what is currently in the literature and demonstrates how these families’ experiences of caring relations reflect a life-course perspective, which has the potential to inform program planning and policy development for their unique needs.

Similar to our findings, future planning has been identified as an important developmental task of these families (Bowey & McGlaughlin, 2007; Ryan et al., 2014). Our study sheds light on a unique aspect of this issue, that is, the role of the adult with ID’s understanding of death and bereavement and the consequences on a parents’ ability to engage in future planning work. Other researchers have explored the area of loss and bereavement and it is recognized that some individuals with ID have difficulty with these concepts (Clute, 2010; Dodd, Dowling, & Hollins, 2005). Hence, policies and associated programs about advance care-planning should be customized to address the difficulties these families may be facing in order to facilitate engagement in future planning. This issue is particularly prudent in this context, given that the relative with ID may outlive their main caregiver, and therefore future planning should be a focus of clinicians’ work with these families.

More broadly, our study demonstrates how the field of ID has the potential to rewrite normative discourse on aging family relations and caregiving. These families, both caregiver and care-receiver, step back from traditional disability discourse and highlight the need for policy, health care, and social services to expand to meet the needs of individuals with ID within the realities of care enacted by aging family members. It is “...the way that family members articulate experiences and awareness of disability in the domain of kinship [that] helps to constitute broader understandings of citizenship in which disability rights are understood as civil rights” (Rapp & Ginsburg, 2001, p. 545). Further, these narratives challenge normative assumptions regarding who provides care in these families; in this regard, the term “caregiver” is not applicable to the lived reality of participants and has been avoided throughout this paper. Rather, it is by focusing on the multiple and complex ways in which family members from different generations rely and intersect with one another in mutual interdependence that we can come to understand how dynamic family relations are embedded within the broader contexts of policy and service provision. Ultimately, it is the intimate biographical knowledge that family members possess and their engagement in long-standing reciprocal care exchange that offers valuable insight on how to best design services and policy to support this unique population as they age in their communities.

There were several limitations of this study. All of the participants lived in urban areas, which limits the representativeness of the findings to families in rural and remote areas. As well, the families were all connected to formal services of some kind, yet there are likely aging families that have not been receiving formal services. In this study, we had one parent–child dyad that participated in an interview together, however, there is very little research in this area that involves familial dyads. Further research which included a larger study sample and included families without formal service support connections would be useful in more robustly understanding the dynamics of the care relations that occur. Further, such findings would be able to more specifically index and inform the requisite policy and programming reforms needed to best support this population.

Conclusion
This study sought to extend understanding of the unique aspects of caring relations in families of community-dwelling aging adults with ID. In these families, the exchange of care does not begin in later life. Rather, it is an ongoing and dynamic process, beginning when a child’s disability manifests and continuing for the duration of the family’s
relationships. With increasing life expectancy of individuals with ID, policy and practice reform and development is required in order to support families as they navigate new terrain in the aging process.

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