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ORIGINAL ARTICLE

How Middle-Aged Siblings of Adults with Intellectual Disability Experience their Roles: a Qualitative Analysis

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Abstract

In many aging families, siblings provide important support to adult brothers or sisters with an intellectual disability. However, this presents new challenges that are affected by past relationships and roles, as well as by the current situation and changes brought on by aging. This study aims to explore the ways in which middle aged typical siblings of adults with intellectual disability shape and perceive their role within the aging family. An interpretive phenomenological analysis was used. Data collection was performed through in-depth, semi-structured interviews with 17 middle aged siblings of adults with intellectual disabilities, followed by a thematic content analysis. Four themes were identified: (1) Sibling multiple roles along the life course; (2) The sibling's role in the changing alignment of aging families living with disabilities; (3) A retrospective examination of the sibling's responsibility; and (4) What does the future hold for siblings? Middle aged siblings in the aging family cope with multiple roles, which may elevate caregiving loads. At this point of their life, middle aged siblings come to acknowledge the complexity of their experience that involves love, compassion, stress, and burden at the same time.

Keywords Sibling role · Intellectual disability · Middle age · Qualitative study · Life course perspective

Theoretical Background

Family carers comprise the largest number of caregivers to adults with disabilities, followed by professional caregivers (American Psychological Association, 2014). As parents age, these families depend increasingly on adult siblings to support the needs of

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the person with the disability, as well as the needs of the aging parents (Coyle et al., 2014). Thus, placing adult siblings of individuals with Intellectual Disabilities (ID) in a precarious turning point juggling their own needs and wishes with the needs and expectations of other family members. At this sensitive junction, roles, that have been constructed over life long siblinghood to an individual with ID, come into play. The aim of the study is to explore the ways in which sibling roles are shaped and perceived within the aging family by middle aged siblings of adults with ID.

Siblings of Adults with ID Experience of their Role

The increasing lifespans of persons with ID and the inadequacies of most adult-service systems (Hodapp et al., 2017) have led to greater attention to the adult siblings of brothers or sisters with ID and the role they play in their lives (Meltzer & Kramer, 2016). A substantial amount of sibling literature has involved the relationship dynamic of the sibling couple (Rossetti & Hall, 2015), the typical sibling's experience (Shivers, 2017), and the influence of disability on the typical sibling (Arnold, & Heller, 2018).

Preliminary research in the area of sibling relationship when one sibling has a disability focused on siblings as caregivers and parental replacements (Bigby, 1998). These studies were influenced by the notion that having a sibling with a disability would lead to negative outcomes for the typically developing sibling (Stoneman, 2005; Stoneman & Brody, 1993). Thus, studies resulting from this line of research have argued that typically developing siblings cope with stress (Egan & Walsh, 2001), burden of care (Roper et al., 2014), lack of parental attention, and other forms of disruption to their life and development (Meltzer & Kramer, 2016). These descriptions of sibling stress and loss have led to the notion that sibling experience when one sibling has a disability has been 'over-pathologized' (Watson et al., 2011), and studies show a one-sided picture of sibling experience on a day-to-day basis. Hence, another body of research has emerged, revealing a more compelling view of sibling experience and roles (Blacher et al., 2013). These studies show how typical siblings can derive a sense of satisfaction, pride, and gratification from the care provider role (Findler & Vardi, 2009), and develop a positive, nurturing, and fulfilling relationship with their brother or sister with ID (Stoneman 2005), thus creating positive outcomes for the typical siblings. Moreover, research has shown that relationships between siblings with and without disability may be equally reciprocal and that they may both give and gain from this relationship (Kramer et al., 2013). This notion paved the way to a more balanced view of the typical sibling's role in the life of the adults with disability (Burke et al., 2015). Thus, some contemporary sibling research suggests that sibling's experience is neither a positive or negative one, but it is a complex and changing reality paved with both hardships and uplifts, ambiguity and confusion, just like any other familial relationship (Pervin, 2018; Gibbons, & Gibbons, 2016; Wofford & Carlson, 2017). This view relies on the social model of disability perspective, which views disability as caused by the way society is organized, rather than by a person's impairment or difference (Oliver, 2013). The social model reviews ways of removing barriers that restrict life choices for individuals with disabilities. Thus, when barriers are removed, people with various impairments can be independent and equal in society, with choice and control over their own lives (Barnes, 2013) and disability is simply another dimension of human difference (Broderick et al., 2005). Studies into sibling roles relying on the social model portray typical siblings as much more than caregivers: they may be friends (Rimmerman and Ralf, 2001), advocates (Burke et al., 2015), mentors (Davys et al., 2010), complementors of formal care (Bigby et al., 2015), and respite providers (Harland & Cuskelly, 2000).

The Life Course Perspective: A Theoretical Framework for Understanding the Typical Middle-Aged Sibling Experience of their Role

Life-course perspective is a theoretical framework that focuses on the historical-social process of families and individuals. It examines how transitions and life paths are linked by way of various family subsystems over different life stages (Elder Jr, 1998). The major premise of this perspective is that the timing of social roles is shaped by various contexts (Macmillan & Copher, 2005). Thus, age norms delineate activities appropriate to each stage of life, providing a sense of when people should accomplish major social role transitions, such as living independently, obtaining employment, getting married, having children, and retiring from work (Esbensen et al., 2012). The accomplishment of these life tasks is not a given for people with disabilities. Some achieve them, whereas others do not integrate into society, due to physical or cognitive impairment, limited skills or social opportunities (Singleton & Darcy, 2013). The life course of siblings of individuals with ID is influenced profoundly by their brother's or sister's disability (Dew et al., 2008). Despite the importance of the adult sibling role in the lives of their brother or sister with ID, the majority of the literature has focused on sibling pairs during childhood and adolescence (Seltzer et al., 2005), and adult siblings have received only little attention (Lee et al., 2018; Lee & Burke, 2018; Rossetti & Hall, 2015). In a comprehensive review of the sibling literature, Heller and Arnold (2010) identified 23 studies regarding adult siblings of individuals with various developmental disabilities. Specifically, they examined psychosocial outcomes of being a sibling, sibling relationships, and future planning. A more recent overview of the sibling literature (Lee & Burke, 2018) has focused on adult sibling caregiving roles, elaborating on both the benefits and hardships of caregiving. Only few studies directly concerned middle-aged siblings (Coyle et al., 2014). These studies revealed that during adulthood, sibling relationships with their brothers and sisters with ID may change in response to their personal situations, characteristics, and supports (Coyle et al., 2014; Knox & Bigby, 2007; Hodapp et al., 2010). Adult siblings face multiple challenges during middle age including the death of family members, the health of their aging parents, and the inclusion of new family members such as in-laws and grandchildren (Knox & Bigby, 2007). During this time, they have their own needs for services and support to assist them in balancing care for their brother or sister, parents and own family (Hodapp et al., 2010). In this context, the life course literature emphasizes issues of transition of care from parents to older siblings (Coyle et al., 2014), sibling's future plans (Seltzer et al., 2005), and multi-generational caregiving models (Holl & Morano, 2014; Miller et al., 2008). However, studies also pinpoint positive outcomes steaming from this experience and indicate that brotherhood or sisterhood to an individual with disability may enhance relationships, deepen bonds with care receivers, increase cohesion among family members who share the experiences, and strengthen or create new socially supportive ties (Gibbons, & Gibbons, 2016; Chen & Greenberg, 2004; Anderson et al., 2017; Kramer et al., 2013).

The aim of the present study is to explore the ways middle aged typical siblings shape and perceive their role within the aging family.

Method

“Interpretive Phenomenological Analysis” (IPA) is a contemporary qualitative methodology committed to the systematic exploration of personal experience (Tutelman et al., 2019). Its objective is to understand lived experiences and explore how individuals make sense of their personal and social worlds; the meanings participants attach to experiences are considered the ‘main currency’ of IPA research (Smith et al., 1999). Through the two complimentary commitments of IPA – ‘giving voice’ and ‘making sense’, researchers seek to attain an ‘insider perspective’ of lived experiences. To do so, IPA draws upon the fundamentals of phenomenology, hermeneutics and ideography (Smith et al., 2009). This approach is used to explore a wide variety of issues including health, illness, and disability (Cassidy et al., 2011; Band-Winterstein & Avieli, 2019).”

Procedure

The research was approved by the university’s ethical board (IRB), as well as by the ethical board of the Welfare Ministry, which oversees the conduct of NGOs involved with adults with disabilities. This approval enabled the researcher to reach out to NGO professionals, explain the study’s aim, and receive a list of potential participants. Consequently, a letter was distributed to siblings inviting them to take part in the research. Finally, the researcher was contacted by siblings who had an interest in participating in the study. Face-to-face interviews took place at the participant’s location of choice – in most cases, in the participant’s home. The duration of the interviews usually lasted from one to two hours. Interview length resulted from two main parameters: the number of questions in the interview guide which was equal for all participants and the details and length of comments provided by the participants which was different in every interview. The interviews were performed by the researcher who is a criminologist and a certified social worker with vast experience in conducting clinical interviews, intake interviews and research interviews. All interviews were transcribed verbatim by a professional transcriber who provided a word by word transcription of the interview (Davidson, 2009).

Participants and Sample

Seventeen siblings of adults with intellectual disability were interviewed. The participants were purposefully selected by criterion sampling (Patton, 2002), to obtain the widest possible variation of respondents among middle age typical siblings who have a brother or sister with a lifelong intellectual disability. A sampling chart was used in order to include various living arrangements, occupational statuses, and marital statuses. Typical sibling ages were between 45 and 65, in accordance with a widely accepted definition of middle age (Dolberg & Ayalon, 2017), with no cognitive deterioration, and good verbal capabilities. Typical sibling mean age was 57 and the mean age of siblings with ID was 59. Additional participant’s information may be viewed in Table 1.

The final sample size (17 siblings) was determined according to Morse's (2000) principle of 'theoretical saturation', which claims that the sample size in phenomenological studies should be determined by the richness and depth of the data gathered from the informants. Thus, in the current study, after 17 participants had been interviewed, recurring content indicated that saturation had been reached (Morse, 1995).

Data Collection

Data collection was performed via individual in-depth, semi-structured interviews using an interview guide (Pietkiewicz & Smith, 2014). The interview guide stems from life course perspective and is based on concepts such as linked lives (e.g.: the way lives of individuals affect and are affected by the lives of others), trajectories (e.g.: a long-term pathway or course of development taken by an individual), and social timing (e.g.: the way age related social values age outline appropriate social roles and transitions) (Elder Jr, 1994; Elder & Giele, 2009). It included four main content categories: *Family relationships over the years* ("How would you characterize your relationship with your sibling over the years?"); *Day-to-day life with disability over the years* ("Can you describe your everyday routine over the years and interactions with other family members?"); *aging alongside disability* ("Now that you are getting older and experiencing a new trajectory in family life, how do you perceive this phase?"); and *Reflecting on the ongoing experience of coping with life-long disability* ("If you could do things differently, what would you change?").

Ethical Considerations

Special provisions were made to ensure informed consent and confidentiality (Dickson-Swift et al. 2007). Freedom to refuse to continue or withdraw from the interview at any point was emphasized. Each participant initially signed a written informed consent form. During the interview the researcher continuously sought process consent for those informants who appeared distressed during the interview (Kavanaugh & Ayres, 1998). In addition, the researcher utilized her professional experience as a social worker to create a candid atmosphere in which the interviewees felt comfortable sharing information (Liamputtong, 2007). To ensure anonymity, any potentially identifying information was removed from this paper. Pseudonyms have been used to replace participant's actual names in order to secure their anonymity on one hand and represent the participants voice in a realistic life-like manner on the other hand (Reyes, 2018).

Data Analysis

First, the researcher read the transcripts a number of times in order to become as familiar as possible with the text. Each reading included initial coding (i.e. pinpointing significant statements). For example, identifying a wide range of sibling feelings towards their sibling with a disability along the life course. This provided first level coding which mainly uses descriptive, low inference codes, that summarise segments of data provide basis for higher order coding (Punch, 2013, p. 174). The next step involved grouping the statements into units of

Table 1 Participants

1	*TS: David	52	Accountant		Married	Independent
	*SWID: Joseph	56	At home	Moderate ID	Single	Family home
2	TS: Sophie	59	Teacher		Widow	Independent
	SWID: Gil	48	Vocational rehabilitation centre	Moderate ID and severe physical disability	Single	Family home
3	TS: Max	65	Physical Therapist		Married	Family home
	SWID: Lucy	55	Vocational rehabilitation centre	Mild ID	Single	Family home
4	TS: Simon	58	Personal trainer		Married	
	SWID: Lora	63	Vocational rehabilitation centre	Moderate ID	Single	Groupe home
5	TS: Rebecca	51	Architect		Divorced	Independent
	SWID: Dan	55	Vocational rehabilitation centre	Severe ID	Single	Family home
6	TS: Sara	62	Cosmetician		Married	Family home
	SWID: Jack	57	Day Centre	Moderate ID	Single	Family home
7	TS: Olivia	47	Retired		Single	Independent
	SWID: Charlie	55	Placement agency for people with disabilities	Mild ID	Single	Family home
8	TS: Celest	50	Nurse		Married	Independent
	SWID: Edi	55	Vocational rehabilitation centre	Moderate ID	Single	Groupe home
9	TS: Romy	54	Homemaker		Married	Independent
	SWID: Ruth	56	Day Centre	Moderate ID and severe physical disability	Single	Family home
10	TS: Denise	57	Engineer		Divorced	Independent
	SWID: Shirley	58	Day Centre	Mild ID and severe physical disability	Single	Family home
11	TS: Leo	50	Marketing Manager		Married	Independent
	SWID: Lucas	52	At home	Moderate ID	Single	Family home
12	TS: Ron	53	Lawyer		Divorced	Independent
	SWID: James	59	At home	Profound ID	Single	Family home

Table 1 (continued)

13	TS: Sharon	66	Retired		Divorced	Independent
	SWID: Steve	70	Day Centre	Severe ID	Single	Nursing Home
14	TS: Eva	65	Retired		Married	Family home
	SWID: Tom	65	At home	Mild ID	Married	Independent
15	TS: Adam	62	Banker		Married	Family home
	SWID: Eliot	70	Day Centre	Mild ID	Single	Nursing Home
16	TS: Anthony	65	Construction worker		Married	
	SWID: Anna	72		Mild ID	Single	Family home
17	TS: Caroline	54	Paediatrician		Married	
	SWID: Jacob	59		Mild ID	Single	Groupe home

*TS: typical Sibling

*SWID: Sibling with Intellectual Disability meaning, including quotes that capture the essential quality of participant experiences and perceptions. For example, gathering quotes relating to sibling roles in the family along the life course. The following step involves identifying connections that are emerging, clustering them together, and conceptualizing them. This stage is also referred to as higher order coding (Elliott, 2018) may be more interpretive, requiring some degree of inference beyond the data and tends to focus on identifying patterns in the participants narratives (Punch, 2013, p. 174). During the text analysis, the researcher aimed to recognize the ways in which accounts from participants were similar but also different. That is, all siblings view themselves as committed to their brother or sister with a disability, but each sibling constructed his or her role differently. Similar constructs were recognized based on the use of concepts, phrases or ideas that were expressed by different participants (Ryan & Bernard, 2003). Finally, the data was organized based on four major themes representing different middle-aged sibling narratives regarding their role (Smith et al., 2009). Adherence to this procedure enhanced credibility (Lincoln & Guba, 2013).

Trustworthiness

Trustworthiness (Lincoln & Guba, 2013) was achieved as follows: First, the researcher read the interviews while using a reflective journal in order to express thoughts, feelings, fears and prejudices. Issues that arose from the reflective journal were then shared and discussed within a group of Colleagues working on similar qualitative research projects, thus enabling bracketing (Wall et al., 2004; Tufford & Newman, 2012). Second, the researcher took part in peer debriefing sessions with a senior clinical social worker from the university staff all along the data collection and data analysis phases of the research. Thereby allowing him to bring in an external perspective on the researcher's interpretations and possible bayas (Lincoln and Guba 2013). Finally, members checking was performed after eight of the seventeen interviews. At the end of these interviews the researcher restated or summarized information as he understood it, and then asked the participant to determine the accuracy of these understandings (Carlson, 2010).

Findings

Data analysis yielded four themes: (1) "*Am I a mother, sister, friend, or daughter?*": Sibling multiple roles along the life course; (2) *"She moves aside now":* The sibling's role in the changing alignment of aging families living with disabilities; (3) *"It isn't a burden, it's just a weight I carry"*: A retrospective examination of the sibling's responsibility; and (4) *"Only my mom knows how to handle him":* What does the future hold for siblings?

Am I a mother, sister, friend, or daughter?": Sibling Multiple Roles along the Life Course

Siblings in families with ID tend to take on multiple roles along the life course as illustrated in the following quote:

> I was never a real child, right from the get-go. I was “a caring mother”. It was always: "Stay with your sister," "Help your sister," "Push your sister’s wheelchair." I remember babysitting for her, feeling responsible, when I was six years old. This became part of my job, part of me. For years I came every morning, although I already had a family. I have kids of my own and everything. I used to come and get Shirley ready, bathing her, getting her organized, and only from there I would go to my work. (Denise, 57)

This sibling describes caregiver roles delegated to her ever since she was a small child. These roles buffered her from experiencing a complete childhood, and they continued to expand, accumulate, and take on greater volume in the sibling’s everyday life routines throughout the years. That is, roles are not replaced one by the other, but rather added, and become an innate part of her everyday life and identity. Another sibling emphasizes his confusion regarding the complexity of multiple roles:

> We grew up together, not just brothers, but friends, close friends despite the disability. But then everybody around us coupled up, all of my friends have children, and when they come over it’s different. I have my wife, my friends that he knows since we were kids, come over with their spouses and children, and he is like sort of stuck at the same stage. So maybe it’s harder for him now, he finds less interest. And for me it's sort of weird, confusing, this feeling that I'm younger than him, but when it comes to significant stuff in life, I somehow pass him. (David, 52)

This sibling is chronologically younger than his brother with ID but faces life trajectories such as getting married and raising children before his brother, and thus becomes “older” than his elder brother. It seems that while during childhood the difference between the siblings was imperceptible, during the life course this gap intensified and left the sibling without ID with a paradoxical sense of leaving his older brother behind, which is both confusing and painful. From the social model of disability perspective, these siblings started feeling estranged from each other only because of social boundaries and not by disability itself.

Another aspect of the multiple roles of siblings is described by a younger sister of a brother with ID:

> You know how teenagers close themselves in the room? Well, in our house my friends used to sit in the living room with my parents, and they [the parents] were so happy that everybody came over, my parents were longing for company, I guess. I was the source of life in our home. When I was young, I used to put on little sketches to make them laugh. Afterwards, I brought those friends home, I felt compelled to bring the life and laughter in. This was my duty. Now that I'm a parent myself, I think what a heavy weight to carry for a child (Sharon, 66).

This sibling holds a complex and nuanced obligation to keep her parents happy and bring a sense of vitality to their life given the stress these parents were under. This was done using a lot of her resources (e.g.: her social network, her time and energy). It seems, that this role was not asked from her, but rather she took it upon herself, from a young age and throughout her life. Now, she can retrospectively evaluate the emotional toll of this added responsibility.

"She moves aside now": The sibling's Role in the Changing Alignment of aging Families Living with Disabilities

Daily caregiving for a person with a disability takes on different meanings as the family ages. Siblings of adults with disabilities often take on the role of leading the family into the new arena of being an aging family as illustrated in the following quote:

> All day, he [the father] picks him up from the bed to the chair, from the chair to the bed, brushes his teeth, and bathes him. I'm trying to convince him that he needs to wake up. I keep telling him, "Dad, you're getting older, there's going to be a time when you won't be able to pick him up anymore." He is somehow blind to it. Now, our goal should be to bring somebody in, a professional caretaker (Sophie, 59)

Sophie simultaneously reflects on her aging family both from an insider and outsider perspective. While her father keeps his routine caregiving tasks, she identifies the physical difficulties and his relentless efforts for his son with disabilities as overwhelming and consuming. The phrase "He needs to wake up" refers to an alarm to all family members to recognize the changes brought by time. Sophie is calling for a re-organization of duties and tasks, based on outsourcing some of the caregiving. From an insider perspective, the use of collective language with "Now our goal should be to bring somebody in" emphasizes her full partnership, physically and emotionally, in sustaining the family.

Another aspect of the sibling's role in introducing the changes of aging to the family relates to shifting caregiving focus from the sibling with ID to the parents' needs:

> I told her, "Mom, you know dad is not going to be his old self anymore, right? So now you need to take care of him, not Ruth. She moves aside now. All the time Ruth, but Ruth is not the issue anymore. At night somebody needs to be here supporting him when he goes to the bathroom. Ruth sleeps through the night, but we have to be here for him now!" Mom says, "I don't need anything. Never mind – just leave and let us be." But she is just ignoring the truth. So it's on me. For many long nights, my other brother and I took turns sleeping here. (Romy, 54)

The change in the father's situation and functioning leads to coping with an increase of caregiving tasks. As a result, this sister struggles on several fronts: her father's new needs, her sister's ongoing needs, and the mother's refusal to acknowledge the additional attention needed by the father. The phrase "She moves aside now" is a call for realignment of family priorities. Again, it is the sibling who is the one to take initiative and serves as the "responsible adult" – she reflects the need to move forward in preparing the family for the changes accompanying aging.

Some siblings described this stage in family life as "passing the torch" of responsibility for the person with ID to them:

> All of a sudden, the burden was on me. Up until a certain point, I was the one helping. But then it changed: my brother and parents got older, and I suddenly felt this weight: it was all on me. He [the sibling with ID] seemed neglected, he was not as clean as he used to be because they couldn't take him to the shower, and it's not their fault. It was obvious that I'm going there daily, and that everybody’s coming over to my place every weekend. I started having some health problems myself. I have four kids of my own, and grandchildren. I was working full time. After a while I had a breakdown. I had to take care of everything. I just collapsed (Sara, 62).

Sara describes a shift of responsibility – from being in a helping position to taking on full responsibility towards her parents and brother. Although Sara is determined to sympathize with her parents, this shift is experienced as an enormous emotional and physical burden. She describes an ongoing intensive routine of juggling between several family subsystems, which left her overwhelmed to the point of breakdown.

“It isn’t a burden, it’s just a weight I carry”: A Retrospective Examination of the sibling’s Responsibility

Common to all siblings in this research is the experience of lifelong responsibility and obligation towards their family member with ID as illustrated in the following quote:

> It just comes naturally to me. This is the way I want my life to be. For me, it isn’t a burden, it’s just a weight I carry. Even though it can be wonderful it is still like being born for royalty, let’s say, born as a Prince. There is weight coming with it. You have a role, even if it’s the most wonderful role in the world, it is still one big role. It’s not just another thing. (Simon, 58)

The sense of responsibility and obligation to caregiving is described as embedded and constructed within the everyday reality of the sibling’s life. The use of the Prince metaphor emphasizes both the significant value of the sibling’s role in the family, and the perception of this role as a whole entity, with its inherited privilege and scripted routines, carrying various facets, both positive and negative. Thus, disability is perceived as yet another aspect of life as mentioned by the social model of disability.

Other siblings shared feelings of frustration that turned into gratitude for the opportunity to take care of a brother over the years:

> I remember myself as a six years old child helping my brother onto the toilet seat. I felt my parent's attention got "sucked" away from me, and I always knew my parent's obligation to him is greater than anything else. But as the years went by and I kept taking care of him and complaining about it [laughs...] … I saw I actually get a lot out of this. I mean, it is a burden, but a burden done with love. Today, I can say I'm obligated to him for the rest of my life. Sometimes, it feels like prison, but I get so much more in return (Ron, 53)

This sibling describes a complex array of feelings when he refers to caring for his brother as a “burden that’s done with love”. This complexity is as hard to convey as it is to live with: On the one hand, he used to complain, crave attention, and live with the notion that he will never be the center of his parent's focus. On the other hand, he never stopped caring for his brother and loving him. The "prison" metaphor functions as the opposite of the "prince" metaphor used previously. However, both metaphors refer to situations in which life circumstances determine one's life course.

Another form of lifelong obligation is illustrated by Adam:

> My parents always thought I shouldn't be in direct contact with the disability stuff. They tried to do as much as they could by themselves or hire some help. They wanted me to have a normal life, and I get it. But it made me feel like an outsider, like the three of them were a team and I wasn't on that team. Today, I know they wanted only the best for me, but in the end I was alone. And now that they are gone, he is stuck with a brother who barely knows him. (Adam, 62)

Adam reflects on his parent's choice of leaving him out of the family's "inner circle". This choice is retrospectively viewed as both compassionate and ultimately wrong. Adam's experience emphasizes the fortitude of living with disability: the reality of disability within the family is intensely felt even when a sibling is allegedly not part of the everyday caregiving. Retrospectively, the parents' attempt to give Adam a "normal" childhood made him an eternal outsider – as a youngster and now as the sole caretaker of his sibling, a role that is strange to him.

"Only my mom knows how to handle him": What Does the Future Hold for Siblings?

All participants in this research were concerned regarding the future. Some described midlife as a "waiting period" before they will be called on to take the center stage, as illustrated by Rebecca:

> I have three kids of my own. It takes a lot of resources, so now it's time for me to take a step back from the family. But I'm always telling my parents: don't worry, when you'll be gone it's going to be on me. They know if they need me, I'm there, in an instant. For now - I'm still the last option. I know it's just a sort of "time out", that I have all of this ahead of me. For now, I'm waiting, "sitting on the bench" – but my eyes and ears are always on them. (Rebecca, 51)

most of the participants in the current study built their own life (e.g.: got education, raised a family, had a career) parallel to caring for their family. However, this time of achieving their own goals is sometime perceived merely a temporary "time out" until they will be called to serve their main mission as family caretakers. Rebecca uses sports metaphors like "time out" and "sitting on the bench" to unfold the complex experience of always being alert and ready to take over. Over time, this reality may be exhausting as it demands constant awareness of another family unit as well as her own partner, children, and career. Another illustration of concerns regarding the future is brought by Leo:

> Only my mom knows how to handle him, and this is quite frightening to me. When he's behaving like this, I get nervous. I just don't understand her way of

> soothing him. I keep telling her that neither I nor my brothers are going to take it upon ourselves. I wanted it to be clear that he is going to be in an Institute. I told her I am not going to ruin another family... If I'm taking him in I'm going to wreck my own family. When he behaves like this only she can take care of him, she or a professional (Leo, 50)

Leo worries regarding coping with uncontrolled future behaviors when he will feel helpless without the soothing presence of his mother. He resolves these feelings of anxiety with a decision to involve professionals in caregiving for his brother, opting not to take him into his home. His words "I am not going to ruin another family" reveal painful memories of family life as well as fear of the future, and a wish to preserve his own family. Leo does not blame his brother, but he draws a distinct line between his parents and himself, stating that caregiving regimes are bound to change.

Another sibling reflects on the future involvement of her own family in caring for her brother with ID in another way:

> "I am the leader of my family. I call the shots. My son already drives, so I make him come in and say hello to him (the brother with ID), check that everything is ok, so that this will be rooted as the norm for the next generation. I don't expect my family to take care of him like I do, but I do expect them to accept him, to take him under consideration, to be involved (Celeste, 50)

Celeste sees herself as a role model for her children and expects them to accept the obligation for their uncle with ID. However, she perceives her responsibility as active and direct involvement in her brother's care, while, when it comes to the next generation, she will be satisfied with acts of consideration and acceptance, and not actual caretaking.

In sum, middle aged siblings cope with multiple issues concerning families living with disabilities in this particular and sensitive period of the life course. At the same time, they carry many roles and serve as both insiders and outsiders to the family unit. As such, they are able to acknowledge the reality of aging and pave the family's way into a new era as an aging family.

Discussion

The increase in life expectancy of adults with ID, along with advances in social integration and deinstitutionalization process of adults with ID (McCarron, et al., 2019; Arnold & Heller, 2018) leads middle-aged siblings to confront questions regarding their life experience in a family raising a child with ID as well as their past, present, and future role in the family (Arnold & Heller, 2018; Coyle et al., 2014; Lee & Burke, 2018). In this context, four main themes were identified. The first theme was "Am I a mother, sister, friend, or daughter?": Sibling multiple roles along the life course. It revealed a complex emotional task as disability constitutes a powerful life trajectory that rearranges roles and developmental processes within the family (Widmer et al., 2013). Thus, role definitions and boundaries in the families represented in the current study tended to be more flexible so adults within the family could ultimately fulfill several roles at the same time. As claimed by the social model of disability (Barnes, 2013), these siblings served not only as caregivers or guardians but had an important role as friends and confidants. This is in line with other research that shows that typical siblings are often required to take on responsibilities beyond their developmental capacities (Davys, 2013; Fleary & Heffer, 2013). A seminal meta-analysis of well-sibling research found evidence that typical siblings were given increased household and caretaking duties and decreased leisure time in 10 of 14 studies reviewed (Lamorey, 1999). These findings echo the concept of parentification, which is defined as a family dynamic wherein a child takes on increased functional or emotional responsibility (Hooper, 2007). In the context of sibling disability, it is suggested that typical siblings may feel obligated to relieve some of the parent's stress either emotionally, as described by some of the participants who as children brought friends home, or physically, by sharing with the parents the daily caregiving tasks (Hooper et al., 2011). These childhood memories shaped the typical sibling's experience. From a life-course perspective (Elder Jr, 1998), while the roles of spouse, parent, and employee are normative for middle-aged adults, strain associated with each role may increase when the role of caregiving, advocating, mentoring or even just being an ally and confidant to a sibling with disability is added to existing roles (Seltzer et al., 2005). The findings suggest that roles are not changed and replaced over the life course, but rather accumulate. Therefore, when a participant simultaneously experiences himself as both the younger and older brother, or a friend and a daughter, these roles are not distinct, nor are they performed at different stages of life. They are all relevant and performed at all times.

Role reversal and blurriness is also manifested throughout the second theme: "She moves aside now": The sibling as a responsible adult in the aging family. The aging years call for rearrangement of roles and responsibilities in the lives of the families that took part in the study. Entering this new era was often recognized by the typical sibling who resumed the role of preparing the family for the next stage in the family's life course. It seems that two polar forces are thus working within the family at the same time – the wish to preserve things as they are, which is represented by the parents and sibling with ID who tend to overlook their own aging process, and the need for change, which is represented by the typical sibling who feels responsible for "waking the family up" to meet the new situation and make necessary changes (such as hire a professional helper). This analysis of the family's situation on the verge of aging is in line with the continuity theory of normal aging (Atchley, 1989), which claims that in making adaptive choices, middle-aged and older adults attempt to preserve and maintain existing internal and external structures. They prefer to accomplish this objective by using strategies tied to their past experiences and social world. According to this perception, change builds on the person's past, and thus change is a part of continuity (Cook, 2018). The participants in the current study, like their parents and siblings, attempt to hold on to and continue with past life structures, as well as persist in caregiving commitments. However, they also change the specific daily regime surrounding it following family spirit and values.

The third theme was "It isn't a burden, it's just a weight you carry": A retrospective examination of the sibling's responsibility. Most of the siblings in the current research viewed disability, in general, and caregiving, in particular, as an innate and central part of family life. The obligation to caregiving seemed embedded in the lives of the participants – whether they take an active part in caregiving or not. This finding corresponds with the social model of disability (Oliver, 2013) as well with "disability by association," which is a form of family ownership of the disability (Burke, 2008, Pp: 89). It is suggested that siblings perceive themselves as affected by disability simply by being a member of a family living with a person with a disability (Burke, 2009). This associative identity with disability may have a direct bearing on the lives of family members. The narratives of the siblings in the current study display their overwhelming empathy and identification with the needs of the person with the disability, as well as the natural way in which the whole family takes part in caregiving along the life course. When siblings were denied taking part in caregiving roles, they seemed to feel somewhat robbed of their identity and family legacy. Thus, considering "disability by association" and the social model of disability, the findings of this research reflect the importance and the strength of family identity and the obligation to caregiving as a key component in the sibling's life and self-image as constructed from early childhood and into their aging years.

Finally, the fourth theme refers to the future of the family and the sibling relationship – "Only my mom knows how to handle him": What does the future hold for siblings? This theme deals with future planning in light of the family legacy of commitment to the sibling with a disability. Typical siblings live in constant tension between their own lives and the needs of their family. Some enjoy extended periods of "time out" before they are called to assist their family in attending to the needs of the aging family. However, concerns regarding the future constantly preoccupy their thoughts. These findings are consistent with studies of siblings taking part in planning the future care of their brother or sister with a disability (Heller & Kramer, 2009; Davys et al., 2016). Similar to the current study, these researches found that some siblings are concerned regarding future coping with their sibling's needs (Benderix & Sivberg, 2007; Orsmond & Seltzer, 2007), and its implication on the typical sibling's family (Davys et al., 2016). The current findings suggest that siblings were committed to their brother or sister with a disability on their own terms and determined to pass on the torch of this commitment to the next generation. For some, this commitment is embedded in everyday life and perceived as an innate part of their being and identity.

Despite their vital contribution to the aging family, as it is presented here, middle-aged siblings of adults with ID have not received much attention in the disability literature. The findings of this study suggest that the sibling population in the aging family may be placed at a sensitive crossroads between the aging parents, the sibling with a disability and the sibling's life tasks. Therefore, it seems important to understand the unique experience of siblings at this point of their life. While caregiving roles occupy a lot of the typical sibling's role, it is not experienced as an obstruction but as an essential part of life in this family, which is done with love and willingness. This does not contradict the fact that some siblings experience strain due to accumulating multiple roles as they approach middle age. That is – it is not possible, to sum up the sibling's experience as good or bad, hard or easy. Rather, it is a complex emotional journey in which caregiving and other more burdensome roles are interwinds with uplifting experiences to form family life. These families, like other families, form an array of ties and obligations which are modified to the needs of each family member, and changes as these needs change (when aging needs appear for example). In this context, the social model of disability (Oliver, 2013) emphasizes that disability may be embedded in the fabric of life and treated like any other personal quality or characteristic a person may have (Barnes, 2013). It seems that growing up and aging alongside a sibling with disabilities constructs an approach which enables typical siblings to accept their multidimensional ever-changing roles as a given.

Limitations and Recommendations for Further Study

This study focused on the middle-aged siblings' experience thereby leaving out of this research the extremely important voices of the adults with ID themselves. These are brought into the discussion only through their siblings' perspective or the needs they display which is a parochial narrow presentation of their experience. Future study may include interviews with siblings with disabilities, and parents to triangulate the findings and achieve a deeper understanding of the dyadic or entire family unit relationship.

The study reached out to families coping with a specific developmental disability, i.e. an Intellectual disability. Interviews with siblings living with other Developmental Disabilities such as Cerebral Palsy or Autism may provide a more accurate in-depth picture of sibling experience and how it differs by disability type and severity.

Finally, the sampling procedures may have limited the diversity of siblings who participated in the study. We approached siblings through NGOs that specialize in caring for adults with ID, thus the findings reflect only the perspectives of siblings who already had some connection with these NGOs. Sampling procedures may be adjusted to expand the diversity of participants by soliciting participation through other multiple and more diverse sources.

Practical Implications

This study concerns a population that has hardly been studied within a very relevant field of families with disables facing their aging years. Middle adulthood seems to be a turning point for typical siblings in which they take on the leading caregiving roles while being involved in getting the family and themselves ready for the future. This may call for professional intervention assisting this transition. The present study can serve as an initial framework which will enable professionals to better understand and relate to the subjective experience of living and aging alongside a sibling with a disability. Interventions may target distinguishing between the various roles performed by the sibling, help them prepare their family for the aging years, and empower them with knowledge and tools to do so. Additionally, the findings of this study suggest that transition into aging should be acknowledged as a whole family effort. Thus, parents and siblings with ID must be involved in the process of preparing for the future, not leaving it to the typical sibling only.

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Compliance with Ethical Standards

Conflicting Interests The authors declare that they have no potential conflict of interest.

Ethical Approval The study has been approved by the ethics committee of the University of Haifa, Israel. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research ethics committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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