

“What’s going to happen to him when we’re gone?”: Uncertainties of mothers of adult children with autism spectrum disorder and intellectual disability

« *Que lui arrivera-t-il quand nous ne serons plus là?* » : *Les incertitudes de mères proche aidantes d’adultes ayant un trouble du spectre de l’autisme et une déficience intellectuelle*

Abstract

Given that individuals with autism spectrum disorder (ASD) and intellectual disability (ID) often remain dependent on parental support as they transition into adulthood, this study sought to understand the lived realities of maternal caregivers to adult children with ASD-ID. Ten mothers of adult children with ASD-ID completed semi-structured interviews. Inductive thematic analysis resulted in three themes related to the uncertainties experienced by mothers of adult children with ASD-ID: (1) aging as a caregiver, (2) residence considerations, and (3) importance of permanency planning. Such uncertainties resulted from mothers simultaneously navigating their own aging process and the continued dependency of their child.

Résumé

Les individus ayant un trouble du spectre de l’autisme (TSA) et une déficience intellectuelle (DI) continuent souvent à dépendre du support de leur parents quand ils atteignent l’âge adulte. Ainsi, cette étude a cherché à comprendre les réalités du quotidien des mères proches aidantes d’adultes ayant un TSA-DI. Dix mères d’enfants adultes ayant un TSA-DI ont réalisé des entrevues semi-structurées. L’analyse thématique inductive a permis de faire

Author Information

Nadine Minott,
Kelly Carr-Kirby,
Kirsten Penrose,
Chad A. Sutherland,
Nadia R. Azar,
Sean Horton

APEX Research Group, Department of
Kinesiology, University of Windsor, Windsor,
ON, Canada

Correspondence:

hortons@uwindsor.ca

Keywords

autism spectrum disorder (ASD),
intellectual disability (ID),
adulthood,
aging,
maternal caregivers

ressortir trois thèmes liés aux incertitudes vécues par les mères d'enfants adultes atteints de TSA-DI : (1) le vieillissement en tant qu'aidant, (2) les considérations reliées au lieu de résidence et (3) l'importance de la planification de l'avenir de leur enfant. Ces incertitudes découlent du fait que les mères doivent gérer leur propre vieillissement en même temps que les réalités liées à la dépendance continue de leur enfant.

Mots-clés : trouble du spectre de l'autisme (TSA), déficience intellectuelle (DI), âge adulte, vieillissement, mères proches aidantes

Introduction

Individuals with autism spectrum disorder (ASD) and an intellectual disability (ID) often remain dependent on parental support as they transition to adulthood (e.g., Marsack-Topolewski & Graves, 2020; Wright et al., 2019). As the aging processes of the child and parental caregiver intersect, concerns related to the future arise, as the parent manages their own age-related declines alongside their child's continued dependency (e.g., Friedman et al., 2013; Wright et al., 2013). Parents, particularly mothers (Romanotto, 2001), experience stress related to their caregiving roles, which, in turn, impacts their quality of life (e.g., Marsack & Hopp, 2019; Marsack-Topolewski & Church, 2019). Notably, mothers, despite numerous stressors, reported that their relationship with their child with ASD was less affected in comparison to fathers (Hartley et al., 2011).

When compared to parents of children without disability, parents of children with ASD report higher levels of stress (Smith et al., 2010), which is intensified by the presence of the child's maladaptive behaviours, poorer functional ability (Marsack-Topolewski & Maragakis, 2021; Zeedyk & Blacher, 2017), the co-occurrence of an ID (Matson & Shoemaker, 2009; Smith et al., 2010), and continued co-residency (e.g., Anderson et al., 2014; Barker et al., 2011). Unique circumstances created by this perpetual 'full nest' produce higher levels of marital strain and divorce rates (Hartley et al., 2010), elevated feelings of depression, helplessness, and fear, increased body mass index, and an exacerbation of chronic conditions (Marsack-Topolewski & Church, 2019; Namkung et al., 2018). However, adaptive strategies are evident among caregivers (e.g., Marsack-Topolewski & Wilson, 2021; Myers et al., 2009), with reliance on spousal and respite support vital for coping and caregiver relief (Marsack & Preethy, 2017; Marsack-Topolewski, 2021). Caregivers have also demonstrated increased acceptance and compassion, a shift in perceptions regarding disability, and new faith or spirituality (Marsack-Topolewski & Wilson, 2021; Myers, 2009). Although middle-aged parents show patterns of adaptation, as caregivers reach 65 years of age a decline in wellbeing is evident (Namkung et al., 2018).

As parents' age increases, concerns related to their capacity to care for themselves and their child arise, as well as the realization that a parent's death is the loss of a key advocate and caretaker (Marsack-Topolewski & Graves, 2020). Despite parents of children with ASD-ID expressing fears associated with the future, related future planning is fraught with apprehension and avoidance (Anderson et al., 2014; Marsack-Topolewski & Graves, 2020). Delaying such a task is a result of concerns related to safety, relinquishing control, and a lack of emotional investment

from other caregivers (Marsack-Topolewski & Graves, 2020), as well as inadequate resources to identify future supports, fears of the unknown, and a preoccupation with current caregiving duties (Marsack & Preethy, 2017; Marsack-Topolewski & Church, 2019; Marsack-Topolewski & Graves, 2020). However, over time, there may be increased pressure to arrange supervised or alternative living arrangements for an adult child to manage caregiving relief and changes to caregiver roles (Marsack-Topolewski & Graves, 2020; Romanotto, 2001). Given the importance of such preparation, the present study sought to understand the lived realities of mothers of adult children with ASD-ID, with a particular focus on the uncertainties that are apparent when examining their lifelong, caregiving roles.

Methods

In this study, we drew upon fundamental qualitative description (Sandelowski, 2000; 2010) and were guided by a relativist ontology and a subjectivist epistemology, in which we acknowledge that one's reality is subjectively created (Bradshaw et al., 2017). Fundamental qualitative description is considered to be particularly constructive for topics that are relevant to policy makers and practitioners (Sandelowski, 2000).

Participants

Ten mothers ($M_{\text{age}} = 47.2$ years; age range = 44 to 64 years) of adult children with ASD-ID ($M_{\text{age}} = 27.6$ years; age range = 23 to 41 years; 10 males, 0 females) were recruited through convenience and snowball sampling (Patton, 2002). Adult children with ASD-ID co-resided with their mother ($n = 6$), resided in supported living ($n = 2$), or lived alone with familial and paid support ($n = 2$). Mothers were either employed ($n = 8$) or retired ($n = 2$), with annual household incomes ranging from \$10,000 to \$150,000. Participants self-identified as Caucasian ($n = 4$), European/Canadian ($n = 2$), Irish ($n = 1$), Canadian ($n = 1$), Person of Color ($n = 1$), and non-disclosed ($n = 1$). Pseudonyms, along with additional demographic information for participants are provided in Table 1.

Table 1

Participant Demographic Information

Pseudonym	Age (years)	Education	Marital Status ¹
Andrea	64	Post-secondary	Married
Abigail	44	Post-secondary	Single
Grace	58	High school	Re-married
Cathleen	53	High school	Married
Carol	56	Post-secondary	Common-law
Rose	50	Post-secondary	Married

Mia	46	Post-secondary	Married
Charlene	44	Post-secondary	Married
Monica	57	Post-secondary	Married
Lorraine	*	Post-secondary	Married

¹ *Marital status was self-defined by participants. As such, participants who identified as 'married' may not have disclosed a previous divorce.*

* *Non-disclosed age of participant*

Procedures

As part of a larger, ongoing research study, the procedures and findings presented herein represent methods and data from the first of two interviews with ten mothers of adult children diagnosed with ASD-ID. For the current study, each participant completed an audio recorded, semi-structured interview (average duration = 68 minutes) conducted by one of two co-authors. To provide a flexible guideline of open-ended questions, an interview guide was followed. Initial questions sought to establish rapport, which were followed by discussion related to the specific purpose of the study. Example questions included: 'What insights have you developed through parenting an adult child with ASD-ID?' and 'As you age, in what role do you see yourself in relation to your child's aging?'. All procedures received ethical clearance from the host university.

Data Analysis

To complete transcription of audio-recorded interviews, Temi, an online speech-to-text software service, was used. Transcripts were then reviewed while simultaneously listening to audio recordings to ensure verbatim accuracy. As a flexible method to identify patterns and themes within the data, inductive thematic analysis was employed (Braun & Clarke, 2006; Voelker & Reel, 2015). Analysis proceeded with data being coded and organized into groups, prior to the development of themes (Braun & Clarke, 2006). Data analysis was led by one author in close collaboration with two co-authors who served as 'critical friends' (Smith & McGannon, 2018). This process, used to enhance rigour, involved multiple meetings consisting of open discussions and constructive feedback related to interpretation of the findings (Smith & McGannon, 2018; Wolcott, 1994).

Results

Three themes related to the uncertainties experienced by mothers of adult children with ASD-ID were identified. Each theme, listed below, is comprised of subthemes and supported by participant quotes provided in Table 2.

- *Aging as a caregiver*, where the unpredictability, yet inevitability of aging was discussed, with a particular focus on age-related declines affecting one's capacity to care for their adult child.

- *Residence considerations*, which exemplifies varying opinions and options when planning living arrangements for adult children with ASD-ID.
- *Importance of permanency planning*, where mothers recognized their child's lifelong dependence, and the necessity to plan for their child's ongoing care when they are no longer able to be the primary caregiver (Romanotto, 2001).

Table 2

Themes Related to the Uncertainties of Mothers of Adult Children with Autism Spectrum Disorder and an Intellectual Disability

Theme	Subtheme	Example Quotation
Aging as a caregiver	Age-related declines affecting mothers' capacity to care for their child	<p>"At 50, I feel like I'm 100... I've been struggling with a lot of health issues and some days I can't move... I recently started having seizures and I'm terrified because I'm like, am I dying? Sometimes I get scared that my body's saying 'screw you' for running us to the end of our course." (Abigail)</p> <p>"If he had to be lifted, as you get older, that becomes harder." (Cathleen)</p>
	Unpredictability and inevitability of aging	<p>"I'm 58 and healthy. There's a lot of people that aren't... and no one knows what's going to happen with their health, you know?" (Grace)</p> <p>"If you have an adult [child] that you are caregiving for, it's a huge responsibility now that you're older. And now I'm on this ride. I don't know when mine's going to end, but I'm cruising.... I'm at the edge. I'm getting closer to the edge of my ride." (Lorraine)</p>
	Residence considerations	<p>The way we've set it up is he has an apartment downstairs and hopefully when my husband and I pass away in the very far future, [his cousins] will come and they'll have the upstairs and he'll have the downstairs... so that's our plan. We don't know if it'll come to fruition. We'll see ...I don't want him to be a burden. I don't want him to be an obligation to anybody." (Mia)</p> <p>"I have never entertained him being in a group home. That's why we sacrificed and bought him a home from an older couple [who] lived next door... He does communicate, but he doesn't always [do so] when there is an issue. You have to visit, and pick up on that, or I rely on the workers that come in... He needs supervision." (Lorraine)</p>
	Group home living arrangements	<p>"[Group home living is] great. He calls 2-3 times a day, tells us how his day is going and he's happy and we're</p>

happy... Parenting [child] now, all we're mainly doing is financial... I wanted him to transition when he was young versus living with us and then trying to do that when he's 50 or 60." (Monica)

"I feel that as I'm getting older, I'm getting more accepting that I'm not going to be making all the decisions about things that are happening in his life... I just think it comes from understanding that, I must approach things as part of a team...[support staff] have insights to my son that I don't have because he doesn't live with us anymore." (Andrea)

Unresolved living arrangements

"We probably could work on having a better plan in place in case something does happen to us... We were at a meeting and one couple was either in their 80s or close to it and they had an adult special needs child... and they had no [plan]... it's like where does he go? So, I certainly want to avoid being in that predicament... When I'm not physically able to do it that is when I'll approach other avenues of what the next step would be at that point." (Cathleen)

"He's been on a waiting list since he was 18. So, it's a 10 to 20 year waiting list and [child] has been on it for seven years." (Grace)

Importance of permanency planning

Recognizing lifelong dependence

"He's not going to grow up and move out because he cannot live on his own 100% without having some supports in place... You must take care of his emotional needs, and his physical needs... So, it's ongoing for me." (Charlene)

"I can't die before my son... And then what happens when I pass away, or my husband passes away? No parent ever wishes for their child to be gone before them, but sometimes when me and my husband talk, we think that would be the best thing. As hard as that is, because what's going to happen to him when we're gone? We don't know, and it's not fair to him." (Mia)

Planning for child's ongoing future care

"When I'm gone, there has to be a plan of action because I mean, the natural progression is that your kids outlive you, so I have to make sure that that's set in place the best I can." (Rose)

"Our worries when we go [is that] we have to set up a different kind of trust account for our finances so that it doesn't come into play of losing [child's government-supported] monthly payments. We also have to have enough financially to pay for anything that [child] might

need after [government support] when they do the room and board, and then we pay a resource fee. So, there's still a big financial drain going. We've had to go through the complex process of what happens if we go, how does the wheel play?" (Monica)

Discussion & Conclusion

Middle-aged mothers of adult children with ASD-ID highlighted the uncertainties they face when navigating their own aging process and the continued dependency of their child. Specifically, participants identified uncertainties related to (1) the possibility of their own age-related declines impeding their capacity to provide care, (2) considerations necessary for securing living arrangements for their adult child, and (3) creating lifelong plans for their child prior to their inability to provide care or eventual death. These findings expand upon recent literature, as mothers of adults with disabilities have shared similar concerns as they recognize their own aging and grapple with unknowns related to their adult child's future care (Marsack-Topolewski & Graves, 2020; Namkung et al., 2018).

Inevitably, parents will undergo their own aging process and associated age-related declines, affecting their ability to provide adequate care and/or financial support to their adult child with a disability (e.g., Friedman et al., 2013; Wright et al., 2013). Unique circumstances experienced by parents of children with ASD may result in withstanding a greater caregiver burden (e.g., Marsack & Hopp, 2019; Marsack-Topolewski, & Church, 2019), which is further exacerbated by the child's maladaptive behaviours often associated with the co-occurrence of an ID (Matson & Shoemaker, 2009; Smith et al., 2010). Coinciding with previous literature (e.g., Friedman et al., 2013; Marsack-Topolewski & Graves, 2020), all mothers in the present study agreed on the importance of preparing for the future, despite displaying various ideas of optimal care and ideal permanency planning for their child. For example, mothers provided complex and varied responses regarding preferred living arrangements for their adult child, which is justified as diverse outcomes associated with residential status have been identified in previous work (Friedman et al., 2013; Krauss et al., 2005; Seltzer et al., 2011). While some mothers were well prepared for a caregiving transition, others had yet to consider an alternative arrangement despite greater satisfaction reported following the creation of a permanency plan (Kim & Chung, 2016). Uncertainty persisted when mothers attempted to describe their future plans for themselves and their adult child, substantiating the need to develop suitable, accessible supports that can be implemented throughout various stages of the life course.

This study addressed a gap in the literature by focusing on adult children with a co-diagnosis of ASD-ID and a caregiving role specific to mothers, thus extending past research where participant pools included children with a broader diagnosis of an IDD (e.g., Namkung et al., 2018; Zeedyk & Blacher, 2017) and familial or parental caregivers in general (e.g., Marsack-Topolewski & Maragakis, 2021; Marsack-Topolewski & Wilson, 2021). Given that Hartley et al. (2011) identified differences between mothers and fathers in their parenting experiences, studies that continue to explore gender differences in this respect will add value to the literature. We recognize that our study is only a snapshot of the lived experience of parenting an adult child with ASD-ID, as mothers were middle-aged with minimal ethnic diversity, and were most often

employed with relatively high socioeconomic status and education levels. Many participants alluded to other families that appeared to be experiencing more extensive struggles, thus suggesting future studies would benefit from a more diverse sample encompassing a greater breadth of ethnicities, socioeconomic circumstances, and education levels, as well as a specific focus on caregivers 65 years of age and older. Furthermore, as our sample included mothers who co-resided with their adult children and mothers of adult children who resided in supported living, future research that investigates the differences in those experiences is warranted. Finally, given that our participants consisted of middle-aged mothers, and that previous research has identified that both the challenges and subjective experiences of parenting a child with an ID changes over time (Barker et al., 2011; Namkung et al., 2018) further exploration as to how mothers adapt over the life course would prove valuable (Esbensen et al., 2012; Hutchison, 2010). Due to the often intensive nature of continuing care for their adult child with ASD-ID, mothers often have a very different aging experience than other aging parents, which may have important social policy considerations. In conclusion, uncertainties experienced by mothers of adults with ASD-ID arise from managing their personal aging process alongside their child's continued dependency. During this challenging time, mothers are required, often with minimal resources and support, to devise future care and residency plans for their child as they confront the unknowns that accompany their future ability to continue their caregiving role.

Key Messages From This Article

People with disabilities: As you age, so do your caregivers. It is important to have a plan for the future, in the case that your current caregiver needs other people to help make sure you receive the support you deserve.

Professionals: Helping mothers of children with disability simultaneously recognize their own aging process and plan for their child's adulthood should incorporate individual preferences and needs.

Policy makers: Policies to ensure mothers have access to resources to create permanency plans for an adult child with disabilities is necessary for the health and well-being of the mother and child.

Acknowledgments

We appreciate the mothers who shared their story with us, as their words are the foundation of this research project. We are also grateful for our on-going partnership with Community Living Essex County.

Messages clés de l'article

Personne en situation de handicap : Tout comme vous, vos aidants vieillissent. Il est important de planifier la suite des choses, comme le moment où votre aidant actuel aura besoin d'autres gens pour assurer la continuité de votre support afin qu'il demeure approprié et réponde à vos besoins.

Professionnels : Pour soutenir adéquatement les mères proches aidantes de personnes en situation de handicap afin qu'elles reconnaissent à la fois le fait qu'elles vieillissent et la nécessité de planifier l'avenir de leur enfant, on doit tenir compte de leurs besoins et préférences individuelles.

Décideurs : Pour voir au bien-être et à la santé des mères proches aidantes de personnes en situation de handicap, on doit élaborer des politiques qui leur assurent l'accès aux ressources nécessaires pour qu'elles puissent planifier et assurer l'avenir de leur enfant d'âge adulte au-delà de leur propre longévité.

References

- Anderson, K., Shattuck, P., Cooper, B., Roux, A., & Wagner, M. (2014). Prevalence and correlates of postsecondary residential status among young adults with an autism spectrum disorder. *Autism, 18*(5), 562-570. <https://doi.org/10.1177/1362361313481860>
- Barker, E., Hartley, S., Mailik Seltzer, M., Floyd, F., Greenberg, J., & Osmond, G. (2011). Trajectories of emotional well-being in mothers of adolescents and adults with autism. *Developmental Psychology, 47*(2), 551-561. <https://doi.org/10.1037/a0021268>
- Bradshaw, C., Atkinson, S., Doody, O. (2017). Employing a qualitative description approach to health care research. *Global Qualitative Nursing Research, 4*, 1-8. <https://doi.org/10.1177/2333393617742282>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. <https://doi.org/10.1191/1478088706qp063oa>
- Esbensen, A. J., Malik, M. R., & Krauss, M. W. (2012). Life course perspectives in intellectual disability research: The case of family caregiving. In J. A. Burack, R. M. Hodapp, G. Iarocci, E. Zigler (Eds.), *The Oxford Handbook of Intellectual Disability and Development* (p. 380-391). Oxford University Press. <https://doi.org/10.1093/oxfordhb/9780195305012.013.0024>
- Friedman, N., Warfield, M., & Parish, S. (2013). Transition to adulthood for individuals with autism spectrum disorder: Current issues and future perspectives. *Neuropsychiatry, 3*(2), 181-192. <https://doi.org/10.2217/npv.13.13>
- Hartley, S.L, Barker, E.T, Seltzer, M.M, Floyd, F., Greenberg, J., Orsmond, G., & Bolt, D. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology, 24*(4), 449-457. <https://doi.org/10.1037/a0019847>
- Hartley, S. L., Barker, E. T., Seltzer, M. M., Greenberg, J. S., & Floyd, F. J. (2011). Marital satisfaction and parenting experiences of mothers and fathers of adolescents and adults with autism. *American Journal of Intellectual and Developmental Disabilities, 116*(1), 81-95. <https://doi.org/10.1352/1944-7558-116.1.81>
- Hutchison, E. D. (2010). A Life Course Perspective. In E. D. Hutchinson (Ed.), *Dimensions of Human Behavior* (4th Edition) (p. 1-38). SAGE Publications.
- Kim, G., & Chung, S. (2016). Elderly mothers of adult children with intellectual disability: An exploration of a stress process model for caregiving satisfaction. *Journal of Applied Research in Intellectual Disabilities, 29*(2), 160-171. <https://doi.org/10.1111/jar.12166>
- Krauss, M., Mailick, M., & Jacobson, H. (2005). Adults with autism living at home or in non-family settings: Positive and negative aspects of residential status. *Journal of Intellectual Disability Research, 49*(Pt 2), 111-124. <https://doi.org/10.1111/j.1365-2788.2004.00599.x>
- Marsack, C., & Hopp, F. (2019). Informal support, health, and burden among parents of adult children with autism. *The Gerontologist, 59*(6), 1112-1121. <https://doi.org/10.1093/geront/gny082>

- Marsack, C., & Preethy, S. (2017). Mediating effects of social support on quality of life for parents of adults with autism. *Journal of Autism and Developmental Disorders, 47*(4), 2378-2389. <https://doi.org/10.1007/s10803-017-3157-6>
- Marsack-Topolewski, C. (2021). Parental caregivers' use of support networks for adults with autism by educational status. *Journal of Family Social Work, 24*(2), 81-97. <https://doi.org/10.1080/10522158.2020.1777239>
- Marsack-Topolewski, C., & Church, H. (2019). Impact of caregiver burden on quality of life for parents of adult children with autism spectrum disorder. *American Journal of Intellectual and Developmental Disabilities, 124*(2), 145-156. <https://doi.org/10.1352/1944-7558-124.2.145>
- Marsack-Topolewski, C., & Graves, J. (2020). "I worry about his future!" Challenges to future planning for adult children with ASD. *Journal of Family Social Work, 23*(1), 71-85. <https://doi.org/10.1080/10522158.2019.1578714>
- Marsack-Topolewski, C., & Maragakis, A. (2021). Relationship between symptom severity and caregiver burden experienced by parents of adults with autism. *Focus on Autism and Other Developmental Disabilities, 36*(1), 57-65. <https://doi.org/10.1177/1088357620956927>
- Marsack-Topolewski, C., & Wilson, K. (2021). Coping strategies used by aging parental caregivers of adults with autism spectrum disorder. *Families in Society: The Journal of Contemporary Social Services, 102*(1), 119-132. <https://doi.org/10.1177/1044389420913121>
- Matson, J., & Shoemaker, M. (2009). Intellectual disability and its relationship to autism spectrum disorders. *Research in Developmental Disabilities, 30*(6), 1107-1114. <https://doi.org/10.1016/j.ridd.2009.06.003>
- Myers, B., Mackintosh, V., & Goin-Kochel, R. (2009). "My greatest joy and my greatest heart ache:" Parents' own words on how having a child in the autism spectrum has affected their lives and their families' lives. *Research in Autism Spectrum Disorders, 3*(3), 670-684. <https://doi.org/10.1016/j.rasd.2009.01.004>
- Namkung, E., Greenberg, J., Mailick, M., & Floyd, F. (2018). Lifelong parenting of adults with developmental disabilities: Growth trends over 20 years in midlife and later life. *American Journal on Intellectual and Developmental Disabilities, 123*(3), 228-240. <https://doi.org/10.1352/1944-7558-123.3.228>
- Patton, M. (2002). *Qualitative research & evaluation methods* (3rd ed.). SAGE Publications.
- Romanotto, C. (2001). *Understanding the well-being of older maternal caregivers of adult-aged children with developmental disabilities* [Unpublished doctoral dissertation]. New York University.
- Sandelowski, M. (2000). Focus on research methods: Whatever happened to qualitative description. *Research in Nursing & Health, 23*, 334-340. [https://doi.org/10.1002/1098-240X\(200008\)23:4<334::AID-NUR9>3.0.CO;2-G](https://doi.org/10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G)
- Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing & Health, 33*(1), 77-84. <https://doi.org/10.1002/nur.20362>

- Seltzer, M., Floyd, F., Song, J., Greenberg, J., & Hong, J. (2011). Midlife and aging parents of adults with intellectual and developmental disabilities: Impacts of lifelong parenting. *American Journal on Intellectual and Developmental Disabilities, 116*(6), 479-499. <https://doi.org/10.1352/1944-7558-116.6.479>
- Smith, L., Hong, J., Mailick Seltzer, M., Greenberg, J., Almeida, D., & Bishop, S. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 40*(2), 167-178. <https://doi.org/10.1007/s10803-009-0844-y>
- Smith, B., & McGannon, K. R. (2018). Developing rigor in qualitative research: Problems and opportunities within sport and exercise psychology. *International Review of Sport and Exercise Psychology, 11*(1), 101-121.
- Voelker, D., & Reel, J. (2015). An inductive thematic analysis of female competitive figure skaters' experiences of weight pressure in sport. *Journal of Clinical Sport Psychology, 9*(4), 297-316. <https://doi.org/10.1123/jcsp.2015-0012>
- Wolcott, H. (1994). *Transforming qualitative data*. SAGE Publications.
- Wright, S., Brooks, D., D'Astous, V., & Grandin, T. (2013). The challenge and promise of autism spectrum disorders in adulthood and aging: A systematic review of the literature (1990 – 2013). *Autism Insights, 20*, 21-73. <https://doi.org/10.4137/AUI.S11072>
- Wright, S., Wright, C., D'astous, V., & Wadsworth, A. (2019). Autism aging. *Gerontology & Geriatrics Education, 40*(3), 322-338. <https://doi.org/10.1080/02701960.2016.1247073>
- Zeedyk, S., & Blacher, J. (2017). Longitudinal correlates of maternal depression among mothers of children with or without intellectual disability. *American Journal on Intellectual and Developmental Disabilities, 122*(5), 374-391. <https://doi.org/10.1352/1944-7558-122.5.374>