ORIGINAL PAPER



In Their Own Words: Mothers Narrate the Lived Experience of Raising Children with Developmental Disorders Who Engage in Socially Disruptive Conduct

Rondalyn Varney Whitney 1,2 10

Accepted: 16 April 2022

© The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature 2022

Abstract

The occupational role of a mother parenting a child with developmental and socially disruptive conduct is unique. *How* mothers express their experiences is poorly explored in the literature. This study aims to better understand mothers' description of their unique experiences in order to better inform interventions. Using a narrative inquiry approach, mothers convey unique stressors related to two central themes (role fulfillment and role support) during a journal writing intervention. Studying mothers' own words as they attempted to make sense of their experiences aligns with the foundational principles of narrative medicine: People make sense of their experiences through storytelling. Knowledge gained from this research underscores the importance of centering a mother's voice in order to create effective interventions.

 $\textbf{Keywords} \ \ \text{Narrative medicine} \cdot \text{Developmental disabilities} \cdot \text{Socially disruptive conduct} \cdot \text{Journal writing} \cdot \text{Maternal stress} \cdot \text{Occupational role of motherhood}$

Introduction

Mothering represents a lifelong occupational role fundamental to the identity of many women. Yet the impact of social isolation, their sense of competence and parenting practices that influence their perception of that role continue be overlooked in research (McLaughlin & Harrison, 2006). Over the past 60 years, mothers in their occupational role as primary caregivers have consistently reported the same set of challenges, including the inability to do the things they enjoy, having someone to talk to who they feel understands their lived experience, and getting help looking after their children during family and community social events (Yamada et al., 2012). Much of their day is spent supporting their child's needs with little time or energy available for personal restorative occupations which can lead to social isolation (DeGrace, 2004). As a result of their needs not being met

and the struggles they face in managing both the physical and emotional demands of being a parent while balancing work and family responsibilities, mothers are especially vulnerable to stress. Maternal stress in particular continues to be a primary predictor of depression and anxiety disorders (Hoffman et al., 2009), and parents who experience chronic stress find it negatively affects both their physical and psychological wellbeing and reduces their overall quality of life (Mariotti, 2015).

Some mothers face considerable additional challenges when raising a child with significant behavioral disabilities. The occupational role of a mother looks very different when they have a child with developmental disorders who engages in socially disruptive conduct and requires special attention. Mothers who attend to the needs of children with socially disruptive conduct spend 3.6 more waking hours of their day caring for their child compared with mothers of typical children (Tunali & Power, 2001) and report feeling socially isolated (Lee et al., 2008) and experience significant psychological distress as a result (Heiman & Berger, 2008). Socially disruptive conduct can isolate the family and limit a mother's ability to work, engage in leisure pursuits, and engage in self-care (Segal, 2000). Davis and Carter (2008) reported 39% of mothers who care for children with socially disruptive behaviors experience acute and chronic

Published online: 08 June 2022



Rondalyn Varney Whitney rondalyn.whitney@quinnipiac.edu; whitneyrondalyn@gmail.com

Department of Occupational Therapy, Quinnipiac University, North Haven Campus, Hamden, CT 06473, USA

² 14 Frazier Road, Hamden, CT 06518, USA

health consequences as a direct result of their occupational role. Mothers raising children with behavioral disabilities have reported lower quality of life (QoL) scores (Yamada et al., 2012), leading to increased chronic stress levels and decreased mental health. Friendship and social networks are negatively impacted in over 60% of families parenting a child who exhibits socially disruptive conduct (Goldstein et al., 2007). Maternal cortisol levels (a measure of stress response) are positively correlated to their child's externalizing behaviors (Seltzer et al., 2009)—at levels paralleled only by individuals with PTSD, combat soldiers, and Holocaust survivors. Forty-five percent of these mothers reported they were taking antidepressants and were over 50% more likely than fathers to be receiving professional help for their stress (Little, 2002).

Women use emotional disclosure as a stress buffer by seeking emotional support, gaining informal counseling and advice from friends, and using their relationships to discharge feelings of anguish and being overwhelmed by role responsibilities (Cacioppo & Patrick, 2009). Yet mothers suffering from isolation—in particular mothers of children with developmental disorders—have long reported feeling unheard and poorly supported by both community and professionals and having limited outlets to share their emotions (Benson, 2006). Where interventions have been proposed, most have aimed at child symptom reduction or enhancing parenting skills and not the needs of the parent (Perry, 2007).

One way to address this glaring gap in maternal care is to have mothers engage in self-narration. Occupational scientists refer to the act of representation as occupational story making (Zemke & Clark, 1996)—the process of telling one's own story as it is lived. Lacking the time to socialize and without an understanding audience who shares the common experience of raising a child with developmental disabilities, mothers can turn to writing about past or current experiences to relieve stress and provide catharsis. The act of writing about personally stressful experiences has been found to enhance physical health and wellbeing (Pennebaker, 1993). As a form of therapy, journal writing has opened doors for individuals to develop a deeper understanding of their thoughts and perceptions of their life experiences (Pennebaker, 2007).

But *how* mothers express what they experience in the occupational role of mother when raising a child with disruptive behaviors is a poorly explored area in the literature. Whitney and Smith (2015) assessed the use of journal writing to help mothers cope with the stress of raising children with developmental disabilities, but the study primarily focused on decreasing maternal stress through an online journaling activity and aimed to understand the quality of the mother–child relationship. Although Whitney and Smith (2015) found that using emotionally charged language was beneficial for this population, the current study

instead analyzed the reported lived experiences of mothers to better understand the common themes expressed in the journal entries of mothers raising children with behavioral disabilities.

Mothers tell a unique story of the occupational role of parenting, and their stories and the process of storytelling (i.e. what we tell ourselves about our life as we are living it) has been described by occupational scientists as occupational story making. Understanding in their own words the occupational experiences of mothers raising children with behavioral disabilities is critical to the development of meaningful occupation-based interventions aimed to promote or restore maternal health. Hearing what each mother has to say about their life story, stressors, perceived support and goals helps establish a more holistic and occupationbased approach for treating this population. As this population is an underserved group that presents with a critical need for therapeutic intervention, knowing what they have to say allows occupational therapy practitioners to make more informed decisions regarding material care.

Methods

Study Design

The purpose of this study is to analyze how mothers describe their experience raising children with behavioral disabilities in order to better identify occupational therapy interventions that will meet their needs. The study used a narrative inquiry approach to examine qualitative research. A narrative inquiry is a phenomenological qualitative research methodology that examines the stories of individuals in order to understand the lived human experience (Clandinin & Connelly, 2004; McCormack, 2004). A narrative inquiry focuses, "not only on individual experiences but also on the social, cultural, and institutional narratives within which individual experiences are constituted, shaped, expressed, and enacted" (Clandinin, 2019). The narrative inquiry design was selected to provide an opportunity for the individual experiences of mothers whose children have a behavioral disability to be heard and allow the researchers to identify common themes that emerge when discussing the unique stressors that this population experiences (Silverman, 2014). Studying mothers' own words is an attempt to make sense of the meanings they bring to their own experiences and aligns with the foundational principles of narrative medicine that people make sense of their experiences through storytelling (Charon, 2001).

Polkinghorne (1995) distinguishes two types of narrative inquiry: narrative-type and paradigmatic-type. The latter uses an analytic procedure to produce taxonomies and categories from the data rendered from gathered stories by



examining the data for common themes and ideas. The paradigmatic approach classifies concepts by a set of attributes shared by its members and distinguishes subordinate categories by the unique attributes. For example 'negative emotions' might include subordinate categories distinguished by unique attributes such as 'feeling depleted' and 'feeling demotivated/disengaged'.

Although a paradigmatic-type narrative inquiry is infrequently used in occupational therapy research, occupational therapists are interested in how human beings engage in purposeful pursuits in the world and this methodology describes the actions of human life through thematically-unified goal-directed actions. In this study, journal entries of mothers explored perceptions of their role, their relationships and their lived experiences parenting children with developmental disabilities. By cataloging what life experiences they thematically share in common, we were able to determine potential occupational therapy interventions that might address the needs of the participants in the study and increase their QoL.

Participants

Mothers of children ages 3 to 18 who were already part of several online parent communities and had self-identified as having a "difficult" or "hard-to-parent child" due to multiple diagnoses were recruited for the study over a 6 month period through internet and clinical communities. Participants were recruited from multiple parent support networks, health professional support groups and related online networks. An electronic flyer along with an introductory recruitment letter was posted or forwarded to parents of children known to have socially disruptive conduct as a result of primary diagnosis. All mothers who wished to enroll in the study were included for a starting sample of N = 156. Participants were asked to read and sign a Letter of Consent before relevant demographic data was collected through a Survey Monkey questionnaire. 77% (n = 120) of the recruited sample completed the demographic questionnaire. The age of the subjects in this study fell between the ages of 31–50 with an annual household income level of over \$60,000. About half were parenting 1 or 2 preschool—middle school-aged children. Most mothers in the sample were working at least part-time, were primarily Caucasian and lived in the United States. The child with disruptive behaviors was primarily male (72%). The primary diagnoses given for the child with disruptive behaviors were Autism (29%), Oppositionality/ ODD (13%) and Sensory Processing Disorder (9.3%). The reported overall maternal stress related to the occupational role of parent was above the threshold of clinically significant levels on the Parenting Stress Index range (n = 113, M = 33.59, SD = 8.212) (Abidin, 1995), and level of difficulty of child behaviors were strongly related to maternal stress (r = .821; p = .001).

Data Collection

Participants engaged in weekly writing sessions for 8 weeks. There was no restriction on the number of sessions mothers could complete per week nor on the time allocated, but participants were encouraged to write for 15 min. Previous research has shown that short bursts of writing (15 min) are sufficient to produce lower stress levels, allows for emotional disclosure yet provides containment of distressing emotionality (Pennebaker, 2007). An open-source server, Global Classroom, was used to upload 8 prompts and return responses in a secure online drop-box. Participants were required to log in and out when writing, registering each of their intervention sessions and allowing the researcher to monitor the number of sessions completed and the date/ time of the participant's writing. The prompts were adapted from previous research (Adams, 1999; Pennebaker, 2007) and are shown in Online Appendix A (found in Supplemental Materials). 39% of the mothers responded to all 8 journal prompts (165 entries).

Coding

Coding, or the process of defining what data is about, is at the foundation of data analysis in qualitative research. This process involves taking the data apart and assigning 'codes' or labels that assign symbolic meaning to 'chunks' of information collected during the study (Miles et al., 2014). Unlike in other research quantitative methodologies, qualitative coding is not developed from pre-conceived categories; instead, codes emerge as the result of researchers studying and interacting with their data. As recommended by Polkinghorne (1995) and following the practices of data analysis using the paradigmatic analytic procedure, the data were analyzed first by being read through twice by the researchers (graduate student and professor with advanced certification in Narrative Medicine), allowing them to become familiar with the data and then to probe for common themes and ideas. This involves generating initial codes through close reading, searching for themes, and defining the themes. The data was analyzed from the perspective of the journal writers by coding for actions using gerunds (e.g., leading, being excited, getting frustrated, etc.). Charon's recommendations in close reading include listening to the story for what is seen, what is heard and what the storyteller is attempting to



¹ Sites included Sensory Street, NLDline, Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD), McNeeds Yahoo Group, OT Connections and The Autism Montgomery of Maryland. Support groups included Kennedy Krieger Institute and Johns Hopkins Medicine—Baltimore.

Table 1 Definitions of themes and sub-themes derived across narratives

Theme/sub-theme	Description
Role fulfillment	Participants' ability to meet role-demands
Role strain	"Difficulty in fulfilling role obligations" (Barton et al., 2013)
Role overload	"When individuals are subject to too many role-demands and have too little time to meet them, it hinders their ability to address all the demands" (Bar & Jarus, 2015)
Advocating for their children	Advocating for their children: publicly supporting or recommending on behalf of their child's needs to be successful
Role support	Participants' access to resources
Emotional	Access to a/an individual(s) that provide a resource to ensure emotional wellbeing
Financial	Access to regular income, employment, savings, programs, etc. to afford raising a family and meeting basic needs and/or personal desires

convey (Charon, 2006). For example, using this approach, generating initial codes through close reading led to 'experiencing negative emotions' which subsumed a wide range of initial codes such as 'feeling bad', 'feeling betrayed', 'feeling angry', 'being frustrated', etc. Deep reading in narrative inquiry also recommends line-by-line coding at the beginning of the research, encouraging researchers to actively engage with the data, bracket their preconceptions, and see it from new perspectives to generate fresh ideas (Charon, 2001). Line-by-line coding was conducted for an initial set of journal entries until a sufficient number of codes were generated to utilize. Codes were then assigned to larger chunks of data such as sentences or paragraphs.

Probing for themes in the journal entries focused on the discovery of common themes and ideas to help create a coherent story and explore relationships among the substantive codes (Silverman, 2014). Thematic coding offers an overarching analytical framework connecting all parts of the coding process (Saldaña, 2009). Thematic analysis conducted across the journal entries identified two central themes with several contributing sub-themes.

The initial coding was performed in two steps. First, notes were taken directly on the printout of journal entries while reviewing the quality of the transcripts. NVivo software program (v12) was used as a data management tool. The edited transcripts were imported into and the software used to generate a detailed initial codebook. The software was used to further analyze, sort and group the codes to create focused thematic codes.²

The uniqueness of narrative inquiry research is achieved by being true to the meanings derived from the narratives. To assure this was met, the emergent themes and their definition were discussed and debated with the primary investigator (professor) until agreement was reached.

² The 'node tree' from Nvivo with full list of initial codes arranged by the first order concepts, second order themes and theoretical categories is available on request.



Results

Thematic analysis revealed two central themes: role fulfillment and role support (see Table 1).

Within role fulfillment sub-themes related to *role strain*, *role overload*, and *advocacy* were detected; sub-themes related to *emotional* and *financial* support were identified under the general theme of role support.

Role Strain

Outside the role as parent, many women raising children with disabilities have external responsibilities that may include (but are not limited to) spouse, employee, volunteer, mother to typically developing children, friend, etc. In these journals, the theme of role strain (feeling stress across *multiple* roles) was present throughout, including mention of the strain felt caring for themselves. One mother wrote her biggest stressor was "...being overweight and out of shape and trying to find a way to prioritize my own life in the midst of all of my other priorities." The word "overwhelmed" was used 16 different times across the collected journal entries, a clear indication that these mothers were experiencing role strain in trying to fulfill their many different roles.

Unsurprisingly, working mothers wrote about the stress of managing time spent with family while fulfilling their external responsibilities. One wrote, "I am working on my master's degree online and it isn't easy trying to complete assignments when my family wants something from me which seems to be all the time." The role as a spouse was also frequently mentioned, with many women writing candidly about both their marital problems and strengths. The issue of finding time for their husbands was present throughout the journal entries (27 mentions), with many mothers longing for "quality time" with their partner away from their daily responsibilities. Others noted the lack of support, often referring to their husband as another "child" needing care (6 instances).

For many mothers, the multifaceted nature of role strain offered no easy remedy. A clear example of the kind of hydra-headed role strain experienced by mothers is seen in the following journal entry:

I have a lot going on in my life. I have an autistic child who needs constant attention and care, not to mention the fact that he has been trying to leave the house at all hours so I'm constantly scared something is going to happen to him, we have serious financial issues that are not going away, I keep worrying about how I'm ever going to afford to pay for college for my daughter, having my mom have [Alzheimer's] and feeling guilty because I can't really help her. So, I feel this general feeling of numbness.

The emotional impact of role strain resonated throughout the entries, with phrases like"needs constant attention," "constantly scared" and "trying to find a way to prioritize my own life in the midst of all of my other priorities" sprinkled throughout what the mothers wrote in describing the many demands they faced in their various and conflicting roles. Another entry captured the emotional costs of the unrelenting demands these mothers faced:

I feel this constant pressure on myself. I feel like I have to work to make money... I feel like I need to be in the gym for a few hours because I feel so fat, I feel like I should be cleaning my house, doing laundry, doing bills, and it's like this constant pressure I keep feeling...

Throughout the journal entries women recorded hiding these feelings, indicating that despite the outward façade of balancing their many roles, mothers found caring for a developmentally disabled child to be enormously stressful and in conflict with their other roles.

Role Overload

Role overload primarily relates to having too many responsibilities within *one* role—in this case in the mothering role. One mother wrote of how her children's demands (both developmentally challenged and not) "can all be too much at times" and how she was constantly "in tears and feeling at a complete loss as to how to cope with the stress." Another wrote of how often she felt "exhaustion," explaining how raising a child with a behavioral disability was all-engrossing: "ALL of him stresses me." A third mother summed up the stress that stems from the occupation of mothering a developmentally challenged child: "I am soooo overwhelmed... this is not working for me."

To be effective, journal writing needs to be an act of emotional disclosure (Pennebaker, 2007). The LIWC calculates the word count per text and provides norms for use

of negative (2.6) and positive (2.7) and a norm for emotional laden vocabulary (4.2) for comparison. Overall, the emotionally laden vocabulary used by mothers in this study was higher (4.89) compared with the norm (SD 1.60, SE .29). Emotionally laden vocabulary used throughout the journals related to their experiences as a mother included (in order of frequency) "trying," "hard," "tired," "happy," "stressed," "sad," "crying," "isolated," "overwhelmed," "guilt," "depressed" and "miserable." The emotional weight of the motherhood role was so stressful that many stay-at-home mothers discussed returning to work as a stress-reduction technique. One wrote how she is looking forward to her children being in school full time so she can "become a working mom and get some of my 'lost' back," illustrating how many of the mothers in the sample were lacking occupational fulfillment in their role as primary caregiver. Prompt #3 asked mothers: Spend 15 min today with your writing. Answer this question: List 3 words that capture your feelings right now. Then complete this sentence: Beneath the surface I find.... Before you end your session, write 3 other words that capture your feelings. An example of a short entry by one mother shows a change in emotion even with a short writing burst:

Before: content, motivated, tired

Answer to the prompt: Beneath the surface I find restlessness and aggravation and worry and confusion and frustration and fear.

After: hope, strength, momentary peace.

Before journaling mothers used emotional language such as scared, frustrated, fearful, helpless, overwhelmed, tired, and drained. Words like dark and alone occurred for several mothers. At the end of the session, mothers listed words including calm, peaceful, joyful; determined, empowered, confident; relieved, less tense, peaceful; inspired, enthusiastic, empowerment. One created a word, "closure-ifer" and added a note "you didn't say I couldn't make up the word!'.

Advocating for Their Child

One particular area where the role of mother to a developmentally disabled child shone through in the journals was in their advocacy for their child. The word *school* was mentioned 190 times throughout the journals, with a majority of the mothers sharing that they felt their children's schooling was insufficient for their needs. One mother wrote, "I am tired of my son having to suffer because the school doesn't have adequate staffing or the teachers have issues." Despite the felt need to be their child's advocate, mothers commonly reported that they did not feel heard by those in charge; however, lacking other avenues of support, many mothers felt they had no other option than to rely on school authorities, further compounding their feelings of inadequacy. One



mother shared her distress and feelings of hopelessness at not being able to meet her daughter's needs:

I feel like I am no longer able to help my daughter with her sadness... I spoke with the guidance counselor, who said she would speak with my daughter to try to offer support and help. Even though I know this was a good decision, I feel like I am failing my daughter because I have been unable to help her with this situation.

Role Support

The lack of support mothers experienced in their role was the other common theme across the journal entries. A lack of emotional support was a primary stressor for many of the mothers in this study, with many women speaking at length about their marriages and managing relationships with their extended families. Most of the women spoke about how they felt alone, with several mentioning how their partner does not understand how to raise their child with special needs. One mother put it this way in an unsent letter she wrote to her husband:

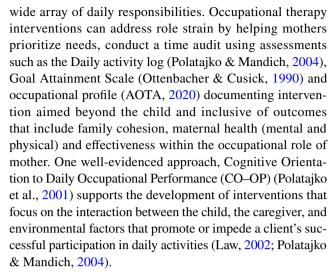
I am so tired of the way you act. I am tired of all the drinking and all the money you spend on alcohol. I am tired of the way you treat me... I am tired of you blaming me for everything. I just want support and help with the kids. I want our kids to have a father. I want to have a husband. I want to be a family.

At the same time financial strains were discussed across the journals, with mothers sharing the difficulties that come with being working and stay-at-home mothers. Typical was the entry one mother wrote about how she is "working three jobs and still not making ends meet," which caused a great deal of stress due to the lack of financial revenue, time spent at work, and the responsibilities as a parent.

Discussion

This study aimed to understand the way mothers describe their lived experience of raising children with disabilities in order to better identify occupational therapy interventions that will meet their needs. Many of the women in the journal entries discussed common causes of stress, specifically in the areas of role fulfillment and perceived support. Their shared insights point the way towards the kinds of occupational therapy interventions that mothers in these circumstances need.

The mothers in this study spoke powerfully about role strain and how it was particularly stressful managing a



Role overload was also found to be a primary area of stress for the mothers parenting a child with behavioral disabilities. Occupational therapy interventions pertaining to role overload could target energy conservation-work simplification strategies to reduce caregiver burden or utilize treatment approaches such as the Personal Engagement Plan (PEP) as outlined in Lifestyle Redesign (Clark, 2015), an activity-based approach to support clients achieve a balanced and sustainable healthy lifestyle within the fabric of his or her everyday roles and routines (USC Mrs.TH, 2020). A lack of role support and stress was also a theme running through the journals. Research supports this finding, as it has been shown that more positive couple interactions are beneficial for children's overall behavior and therefore maternal stress levels (Goldberg & Carlson, 2014). Occupational therapy interventions with respect to role support could include identification of community resources and support with self-advocacy.

As the incidents of pediatric psychopathology climb, more mothers are consequentially attempting to orchestrate families dealing with disruptive, non-engaging and socially challenged children. This marks a significant number of mothers attempting to parent children with unrelenting, demanding, socially disruptive conduct while living with the distress of that circumstance and often in isolation. Mothers appear to be particularly sensitive to the effects of social isolation and uniquely supported by opportunities in the environment to emotionally disclose when experiencing role-related stress. Journaling offered a unique avenue for these mothers in that regard; as one mother put it, before completing the journal entry she felt "tired, frustrated, and worried" but after writing she felt "calm, peaceful, joyful," suggesting that after journaling about her feelings regarding motherhood she was able to feel more at ease. Occupational therapy interventions should take note of this modality and its ability to be delivered online as a promising avenue for addressing the needs of mothers in this role.



In terms of limitations, it is important to note that the data was collected prior to the 2019 pandemic and the widespread societal strain. Future research to assess level of maternal stress during the pandemic would be important to understand the unique way COVID-19 impacted mothers of children with developmental disorders. Additional limitation of this study includes the mothers in the sample self-identified as having children with behavioral disabilities but there was no mechanism in place for verifying whether or not the sample population was accurately representative. Not all mothers participated in each of the writing prompts provided and actual time on task was not recorded in this study. A stronger methodology might expand the number of prompts and time responses, potentially allowing for greater disclosure to occur. In addition, the writing prompts were novel and developed for this intervention; while consistent with previous structured writing (Adams, 1999), the validity of the prompts was not determined prior to the study. Finally, there is the potential for response bias. Participants might have been unfamiliar or uncomfortable with the process of journal writing and thus feel hesitant to fully express themselves or tempered their responses to guard against the disclosure of strong emotions.

Conclusions

Quintessentially, occupational therapy focuses on outcomes of participation and facilitating meaningful engagement in everyday occupations (Law, 2002). Knowledge gained from this research of the lived experience of mothers within their occupational role of parenting children with disruptive behaviors is critical to occupation-based intervention. The aim of this study was to share the stories mothers tell of the lived experience of parenting such children. Developing an understanding of how mothers perceive their own participation is urgent for occupational therapists to create meaningful and purposeful interventions. More, journal writing has been shown to be a powerful tool in stress reduction and can be used more broadly to help improve health and wellbeing, especially for at risk populations like mothers (Whitney & Smith, 2015).

The key practice implications from these findings are three-fold. First, maternal storytelling provides valuable insight into the occupational role of motherhood and is a useful window into developing outcomes of participation and facilitating meaningful engagement in everyday occupations. Second, the importance of a mother's perception must not be underestimated in effective goal setting and occupation-based outcomes. And finally, recognizing the lived experience of raising children with disruptive behaviors may lead to improved occupational participation resulting

in reduced maternal stress and overall health and wellbeing of the mother.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s10803-022-05578-z.

Acknowledgments The author would like to express appreciation to Dr. Olson Pook for his valuable and constructive suggestions during the development of this manuscript. Special appreciation is extended to Juliette Mack, whose assistance with the preliminary process of thematic analysis is greatly appreciated. Finally, special thanks to WVU Community Engagement Grant for providing funding for the NVivo Software program, essential in the analysis of this data.

Author contributions R Whitney designed, directed, and drafted the manuscript for this study; Olson Pook assisted in the revision of the manuscript.

Declarations

Conflict of interest The authors report no conflict of interest.

Research Involving Human Participants and/or Animals Data used in this study was derived from a larger intervention study. Participants in that study were asked to read and sign a Letter of Consent before relevant demographic data was collected through a Survey Monkey questionnaire. As with all studies involving human subjects, a full board review (IRB) was conducted to assure protection of human subjects. An application for Institutional Review Board (IRB) approval was submitted to and granted by TUI University. All effort was made to assure the protection of human subjects in this study. Participants were informed that their participation was completely voluntary. Prospective research participants were fully informed about the procedures and risks involved in this research project, as well as their right to withdraw from the study at any point in time. Subjects were assured confidentiality and anonymity of their participation in the study. To further assure confidentiality, a graduate assistant served in the role of Research Assistant, de-identifying all data before this researcher saw it and, as a result, no journal entry was linked to a participant by name during the study. This larger study appeared in the Journal of Autism and Related Disorders in 2015 (Whitney, R.V., & Smith, G. (2015). Emotional disclosure through journal writing: Telehealth intervention for maternal stress and mother-child relationships. Journal of Autism & Developmental Disorders, 45(11), 3734–3745).

Informed Consent for this Study This study, an analysis of de-identified journal entries of the participants from a previous study, was submitted to the WVU IRB and determined to be exempt (i.e. did not involve human subjects).

References

Abidin, R. R. (1995). *Parenting stress index manual* (3rd ed.). Psychological Assessment Resources Inc.

Adams, K. (1999). Writing as therapy. *Counseling and Human Development*, 31(5), 1–16.

American Occupational Therapy Association [AOTA]. (2020). Occupational therapy practice framework: Domain and process (4th ed.). *American Journal of Occupational Therapy*, 74(Suppl. 2).

Bar, M. A., & Jarus, T. (2015). The effort of engagement in everyday occupations, role overload, and social support on health and



- life satisfaction among mothers. *International Environmental Research and Public Health*, 12(6), 6045–6065. https://doi.org/10.3390/ijerph120606045
- Barton, R., Corban, A., Herrli-Warner, L., McClain, E., Riehle, D., & Tinner, E. (2013). Role strain in occupational therapy fieldwork educators. School of Occupational Therapy, University of Indianapolis. https://doi.org/10.3233/WOR-121508
- Benson, P. R. (2006). The Impact of child symptom severity on depressed mood among parents of children with ASD. Autism Developmental Disorders, 36, 685–695.
- Cacioppo, J., & Patrick, W. (2009). Loneliness: Human nature and the need for social connection. W.W. Norton & Company.
- Charon, R. (2001). Narrative medicine: A model for empathy, reflection, profession, and trust. *JAMA*, 286(15), 1897. https://doi.org/10.1001/jama.286.15.1897
- Charon, R. (2006). *Narrative medicine: Honoring the stories of illness*. Oxford University Press.
- Clandinin, D. J. (2019). Journeys in narrative inquiry: The selected works of D. Jean Clandinin (1st ed.). Routledge. https://doi.org/ 10.4324/9780429273896
- Clandinin, D. J., & Connelly, F. M. (2004). Narrative Inquiry: Experience and story in qualitative research. Jossey-Bass.
- Clark, F. A. (2015). Lifestyle redesign. The intervention tested in the USC well elderly studies. AOTA Press.
- Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Developmental Disorders*, 38, 1278–1291.
- DeGrace, B. (2004). The everyday occupations of families with children with autism. *American Journal of Occupational Therapy*, 58(5), 341–419.
- Goldberg, J. S., & Carlson, M. J. (2014). Parents' relationship quality and children's behavior in stable married and cohabitating families. *Journal of Marriage and Family*, 76(4), 763–777.
- Goldstein, L. H., Harvey, E. A., & Freidman-Weieneth, J. L. (2007). Examining subtypes of behavior among 3-year-old children, Part III: Investigating differences in parenting practices and parenting stress. *Journal of Abnormal Child Psychology*, 35, 125–136.
- Heiman, T., & Berger, O. (2008). Parents of children with Asperger syndrome or learning disabilities: Family environment and social support. Research in Developmental Disabilities, 29, 289–300.
- Hoffman, C., Sweeney, D., Hodge, D., Lopez-Wagner, M., & Looney, L. (2009). Parenting stress and closeness: Mothers of typically developing children and mothers of children with autism. Focus on Autism and Other Developmental Disabilities, 24(3), 178–187.
- Law, M. (2002). Participation in the occupations of everyday life. *The American Journal of Occupational Therapy*, 56(6), 640–649. https://doi.org/10.5014/ajot.56.6.640
- Lee, L., Harrington, R., Louie, B., & Newschaffer, C. (2008). Children with autism: Quality of life and parental concerns. *Journal of Autism and Developmental Disorders*, 38(6), 1147–1160.
- Little, L. (2002). Differences in stress and coping for mothers and fathers of children with Asperger's syndrome and nonverbal learning disorders. *Pediatric Nursing*, 28(6), 565.
- Mariotti, A. (2015). The effects of chronic stress on health: New insights into the molecular mechanisms of brain-body communication. *Future Science*, 1(3), FSO23.
- McCormack, C. (2004). Storying stories: A narrative approach to indepth interview conversations. *International Journal of Social Research Methodology*, 7(3), 219–236.

- McLaughlin, D. P., & Harrison, C. A. (2006). Parenting practices of mothers of children with ADHD: The role of maternal and child factors. *Child and Adolescent Mental Health*, 11, 82–88.
- Miles, M. B., Huberman, A. M., & Saldaña, J. (2014). *Qualitative data analysis: A methods sourcebook* (3rd ed.). Sage.
- Ottenbacher, K., & Cusick, A. (1990). Goal attainment scaling as a method of clinical service evaluation. *American Journal of Occu*pational Therapy, 44(6), 519–525.
- Pennebaker, J. (2007). *Emotion, disclosure and health* (5th ed.). American Psychological Services.
- Pennebaker, J. W. (1993). Putting stress into words: Health, linguistic, and therapeutic implications. *Behavior Research and Therapy*, 31(6), 539–548.
- Perry, D. F. (2007). A missed opportunity: Categorical programs fail to meet the needs of young children and their caregivers. *Journal of Early Intervention*, 29(2), 107–110.
- Polatajko, H. J., & Mandich, A. D. (2004). Enabling occupation in children: The Cognitive Orientation to daily Occupational Performance (CO–OP) approach. CAOT Publications.
- Polatajko, H. J., Mandich, A. D., Miller, L. T., & Macnab, J. J. (2001). Cognitive Orientation to daily Occupational Performance (CO–OP): Part II—The evidence. *Physical and Occupational Therapy in Pediatrics*, 20, 83–106.
- Polkinghorne, D. E. (1995). Narrative configuration in qualitative analysis. In J. A. Hatch & R. Wisniewski (Eds.), *Life history and narrative*. Falmer Press, Taylor & Francis Inc.
- Saldaña, J. (2009). The Coding Manual for Qualitative Researchers.

 Sage.
- Segal, R. (2000). Adaptive strategies of mothers with children with attention deficit hyperactivity disorder. *American Journal of Occupational Therapy*, 54(3), 300–306.
- Seltzer, M., Almeida, D., Greenberg, J., Savla, J., Stawski, R., Hong, J., & Taylor, J. (2009). Psycho social and biological markers of daily lives of midlife parents of children with disabilities. *Journal of Health and Social Behavior*, 50(1), 1–15.
- Silverman, D. (2014). Interpreting qualitative data (5th ed.). SAGE Publications.
- Tunali, B., & Power, T. G. (2001). Coping by redefinition: Cognitive appraisals in mothers of children with and without autism. *Journal* of Autism and Developmental Disorders, 32, 25–34.
- USC Mrs, TH. (2020). Chan Division of Occupational Science and Occupational Therapy. About Health Coaching. Retrieved from http://chan.usc.edu/patient-care/faculty-practice/about.
- Whitney, R. V., & Smith, G. (2015). Emotional disclosure through journal writing: Telehealth intervention for maternal stress and mother-child relationships. *Journal of Autism & Developmental Disorders*, 45(11), 3734–3745.
- Yamada, A., Kato, M., Suzuki, M., Suzuki, M., Watanabe, N., Akechi, T., & Furukawa, T. A. (2012). Quality of life of parents raising children with pervasive developmental disorders. *BioMed Central Psychiatry*, 12(119), 1–8.
- Zemke, R., & Clark, F. (1996). Occupational science: The evolving discipline. FA Davis.
- **Publisher's Note** Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

